



Follow-up & continuing care



european standards of
care for newborn health

EFGNI european foundation for
the care of newborn infants

Topic Expert Group
Follow-up & continuing care

Table of Contents

Overview	2
Assessment of visual function	4
Cognitive development	11
Communication, speech, and language	17
Coordination and integration of care after discharge home	24
Healthy lifestyle and cardiovascular risk factors	30
Hearing screening	35
Immunisation of preterm infants	41
Meeting special needs at school	49
Mental health	56
Motor and neurological follow-up assessment	62
Parent mental health	69
Peer and sibling relationships	75
Post-discharge responsive parenting programmes	81
Reproductive counselling	87
Respiratory outcome	91
Transition from hospital to home	97

Topic Expert Group: Follow-up & continuing care

Overview

There is consistent evidence that preterm birth is associated with a higher risk of adverse long-term sequelae. (1,2) Overall, the earlier a baby is born (i.e. at lower gestation), and the more impaired the fetal growth during pregnancy, the less developed the organs are and the higher the risk for long-term disability. There is consensus that those born very preterm (<32 weeks gestation) or with severe neonatal complications are at high risk. (3) Therefore, the target groups for the standards developed in this topic expert group are the following:

- Infants born before 32+0 weeks' gestation or
- Infants born after 32+0 gestation and has or had one or more significant risk factors such as:
 - a brain lesion on neuroimaging likely to be associated with developmental problems or disorders (for example, grade 3 or 4 intraventricular haemorrhage or cystic periventricular leukomalacia)
 - grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period
 - neonatal bacterial or viral meningitis/encephalitis
 - severe foetal growth restriction
 - known severe social or family problems with issues safety for the child.

Targeted structured follow-up systems and continuing care for this vulnerable patient group, starting in the neonatal unit with discharge management and support during the transition period from hospital to home is thus recommended. (4)

Care programmes for high-risk infants may involve a range of professionals and disciplines. (5) Growth, feeding, general health, visual, hearing, and speech difficulties, as well as cognitive, behavioural and motor development are addressed in all infants, and interventions, such as family-centred developmental support or physiotherapy, (preverbal) speech therapy, dietetics, occupational therapy, or psychological support are advised if appropriate. (6–8) Multidisciplinary collaboration and coordination of care between professionals in different healthcare settings is necessary to prevent families falling through gaps in care and to avoid needless treatment duplication. (9–11) Additionally, assessment of mental health should be included in the follow-up programme, as both, infants born very preterm and their parents are at increased risk for mental health problems. (12,13) Also the risk for developing late-life “cardiometabolic disease” is likely to be increased in children and adults born very preterm, which makes counselling on healthy lifestyle necessary. (14)

Case managers are recommended to provide coordination and continuity of care and treatment goals, and facilitate access to appropriate resources. (15) The focus of care changes over time from medical problems, feeding and growth, to psychological development and educational issues such as behaviour and emotions, interaction with peers and siblings as well as schooling and transition into school.

The Topic Expert Group on Follow-up and continuing care outlines standards for the care and treatment of high-risk babies and children after discharge from hospital and defines central areas of assessments to timely identify problems, and thereby enable appropriate interventions and optimal management of healthcare needs, aiming to improve outcome into adult life.

Source

1. Keller M, Saugstad OD, van Steenbrugge G, Mader S, Thiele N. Caring for Tomorrow. EFCNI White Paper on Maternal and Newborn Health and Aftercare Services [Internet]. European Foundation for the Care of Newborn Infants (EFCNI); 2011. Available from: http://www.efcni.org/fileadmin/Daten/Web/Brochures_Reports_Factsheets_Position_Papers/EFCNI_White_Paper/EFCNI_WP_01-26-12FIN.pdf
2. Johnson S, Wolke D. Prematurity and low birthweight. In: Hopkins B, Geangu E, Linkenauger S, editors. The Cambridge Encyclopedia of Child Development [Internet]. 2nd ed. Cambridge University Press; 2017 [cited 2018 Nov 22]. p. 705–16. Available from: https://www.cambridge.org/core/product/identifier/9781316216491%23CN-bp-101/type/book_part
3. Platt MJ. Outcomes in preterm infants. Public Health. 2014 May;128(5):399–403.
4. Denizot S, Fleury J, Caillaux G, Rouger V, Rozé J-C, Gras-Le Guen C. Hospital initiation of a vaccinal schedule improves the long-term vaccinal coverage of ex-preterm children. Vaccine. 2011 Jan 10;29(3):382–6.
5. Doyle LW, Anderson PJ, Battin M, Bowen JR, Brown N, Callanan C, et al. Long term follow up of high risk children: who, why and how? BMC Pediatr. 2014 Nov 17;14:279.
6. LaHood A, Bryant C. Outpatient Care of the Premature Infant. Am Fam Physician. 2007 Oct 15;76(8):1159–64.
7. National Perinatal Association. Multidisciplinary Guidelines for the Care of Late Preterm Infants. [Internet]. Lonedell, MO; [cited 2017 Mar 5]. Available from: <http://www.nationalperinatal.org/Resources/LatePretermGuidelinesNPA.pdf>
8. NICE guideline. Developmental follow-up of children and young people born preterm (NG 72) [Internet]. National Institute for Health and Clinical Excellence; 2017. Available from: <https://www.nice.org.uk/guidance/ng72>
9. Law J, McCann D, O'May F. Managing change in the care of children with complex needs: healthcare providers' perspectives. J Adv Nurs. 2011 Dec;67(12):2551–60.
10. Woods S, Riley P. A role for community health care providers in neonatal follow-up. Paediatr Child Health. 2006 May;11(5):301–2.
11. Moyer VA, Singh H, Finkel KL, Giardino AP. Transitions from neonatal intensive care unit to ambulatory care: description and evaluation of the proactive risk assessment process. Qual Saf Health Care. 2010 Oct;19 Suppl 3:i26-30.
12. Lindström K, Lindblad F, Hjern A. Psychiatric morbidity in adolescents and young adults born preterm: a Swedish national cohort study. Pediatrics. 2009 Jan;123(1):e47-53.
13. Ionio C, Colombo C, Brazzoduro V, Mascheroni E, Confalonieri E, Castoldi F, et al. Mothers and fathers in NICU: The impact of preterm birth on parental distress. Eur J Psychol. 2016 Nov 18;12(4):604–21.
14. Parkinson JRC, Hyde MJ, Gale C, Santhakumaran S, Modi N. Preterm birth and the metabolic syndrome in adult life: a systematic review and meta-analysis. Pediatrics. 2013 Apr;131(4):e1240-1263.
15. Sauve R, Lee SK. Neonatal follow-up programs and follow-up studies: Historical and current perspectives. Paediatr Child Health. 2006 May;11(5):267–70.

Assessment of visual function

Ortibus E, Leemhuis AG, Wolke D, Termote J, Cassiman C, Geldof C

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care) and parents

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

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.

Rationale

The goal is to assess and evaluate the development of visual and visual information processing functions in order to identify those who could benefit from additional support. Preterm born infants have an increased risk of visual dysfunctions, in particular those with severe brain injury and those who suffered from severe and/or treated retinopathy of prematurity (ROP). Long-term follow-up showed that an adverse ophthalmological outcome (AOO) (reduced acuity, strabismus, high myopia, colour defect, field defect and/or subnormal contrast sensitivity) is present in 25-50% of preterm infants with a birth weight <1500 g. (1,2) Infants who suffered from grade 2 or 3 hypoxic ischaemic encephalopathy or meningoencephalitis have an increased risk of (cerebral) visual impairment (7-11% and 17% respectively). (3,4) Impairments include dysfunctions in visual sensory, oculomotor and perceptive (such as object recognition and spatial processing) functioning. Both visual sensory and visual perceptive dysfunctions exert a negative effect on neuropsychological outcome and academic skills such as reading, writing and maths achievement. (5-8)

Severe visual sensory and oculomotor deficits mostly become visible at early ages. However, visual screening is most reliable at the age of 3.5 to 4 years. At 5 to 6 years, most visual sensory and oculomotor problems have become apparent. If there is suspicion of visual perceptive dysfunctions, standardised examinations can be done from 5 years of age onwards.

Refractive error can often be corrected. Strabismic amblyopia needs to be corrected at an early stage with patching. The treatment or support of visual perceptual deficits, aims to offer the child the best environment to improve its visual functioning and to learn strategies to cope with its specific deficits.

Benefits

Short-term benefits

N/A

Long-term benefits

- Early diagnosis of visual impairment promotes timely interventions (9)
- Promotes realistic expectations in those with severe impairment (consensus)
- Improved decision making for schooling and learning support (consensus)
- Provides feedback to perinatal and neonatal services and healthcare officials (consensus)

- Reduced risk of misdiagnoses (e.g. reading difficulties) (consensus)
- Improved parent-infant interaction adapted to visual ability (consensus)
- Improved academic outcome (10)
- Improved social integration and quality of life (2)
- Reduced social burden and costs (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including visual assessments (including ages at which visual follow-up takes place and the provider thereof). (2)	A (High quality) B (High quality)	Patient information sheet
2. Parents receive standardised feedback about the results of their child's visual health screening in a language that is accessible to them.	B (High quality)	Parent feedback
3. Parents are informed about the need for early intervention and support in case of visual impairments.	B (High quality)	Patient information sheet
4. Parents are asked for permission to allow their child's medical and educational information to be used for outcome measures.	B (Low quality)	Parent consent, patient information sheet
5. Parents are asked to consent to share the results of their child's visual screening tests with education services.	B (Moderate quality)	Parent consent
For healthcare professionals		
6. A guideline on follow-up programme including visual assessment is adhered to by all healthcare professionals.	B (High quality)	Guideline
7. Training on standardised visual assessment in high-risk infants in which gestational age, ROP status, and brain damage are taken into account is attended by all responsible healthcare professionals. (1,2,11–13)	A (High quality) B (High quality)	Training documentation
8. Children with ROP grade ≤ 2 undergo ophthalmologic screening at 3.5-4 years and assessment of visual acuity at 4-5 years; at younger ages, children with signs of adverse visual development are	A (High quality) B (High quality)	Guideline

referred directly to the ophthalmologist. (1,2,10,13)

9. Children with ROP grades 3 and 4 (or treated for any grade of ROP) and with severe brain damage have regular follow-up assessments at the discretion of the ophthalmologist and are at least screened for strabismus and refractive errors at 12 months. (14)	A (High quality)	Guideline
10. Children with clinical suspicion for visual perception dysfunctions are assessed at 5 years of age onwards. (15)	A (High quality)	Audit report
For neonatal unit, hospital and follow-up team		
11. A guideline on follow-up programme including visual assessment is available and regularly updated.	B (High quality)	Guideline
12. A follow-up programme after discharge including visual assessment is funded and supported.	B (Moderate quality)	Audit report
13. Training on standardised visual assessment in high-risk infants is ensured.	B (High quality)	Training documentation
For health service		
14. A national guideline on follow-up programme including visual assessment is available and regularly updated.	B (High quality)	Guideline
15. A follow-up service including visual assessment is specified, funded and monitored.	B (Moderate quality)	Audit report

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
• Offer visual follow-up until adult age. (16)	B (Moderate quality)
• Families are supported by case manager in order to ensure follow-up programme including visual assessments.	B (High quality)
For healthcare professionals	
N/A	
For neonatal unit and follow-up team	
• Establish an integrated electronic system with follow-up provider to schedule follow-up visits.	B (Moderate quality)

For hospital and follow-up team

- Establish multidisciplinary teams, including ophthalmologist/neuropsychologist specialised in visual perception, to evaluate high-risk children. (2) B (Moderate quality)

For health service

- Support the development of reliable and valid instruments to assess cerebral visual deficits with country specific norms and facilitate differential diagnosis. (11,15) A (High quality)
B (High quality)
- Develop a national network for benchmarking of follow-up quality. B (Moderate quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about the risks to vision after high-risk birth and about the follow-up programme.

For healthcare professionals

- Attend appropriate training on standardised visual assessment.
- Establish a structure of communication with other healthcare institutions, providing follow-up care.

For neonatal unit and follow-up team

- Develop and implement a guideline on follow-up programme including visual assessment.
- Develop information material about importance of visual follow-up assessment for parents.
- Establish at least a formal system of keeping track of families.
- Develop a structure of follow-up locally.

For hospital and follow-up team

- Support healthcare professionals to participate in training on standardised visual assessments.
- Ensure ophthalmologists are available and trained in visual sequelae of high-risk births.

For health service

- Develop and implement a national guideline on follow-up programme including visual assessment.
- Make a policy decision that visual follow-up services is standard of care for all infants.

Description

Retinopathy of prematurity (ROP) is an important cause of visual impairment in the preterm infant, and is due to disorganized vascular development of the retina usually after retinal ischaemia consequent to oxygen exposure. Infants who develop ROP are at increased risk of ophthalmological deficits such as refractive error (up to 64%), amblyopia and strabismus (36-44%). (17) However, these disorders are also prevalent in those born under 32 weeks without ROP, in whom refractive errors are present in 26% of infants, amblyopia in 21% and strabismus in 16-20%. (11) In preterm children attending mainstream school, decreased visual acuity was reported

to occur two to three times more frequently than in term-born peers, principally due to refractive errors. High myopia and anisometropia, in particular, confer a risk for developing amblyopia and strabismus. Such early reductions of visual acuity are reportedly subject to “catch-up” by age 5 years, following timely treatment. (17) Weight at birth, head circumference at birth and head circumference at 5,5 years seem to be important contributing factors. (18)

Premature infants are born in a phase of rapid brain growth and organisation. Alterations of brain development have been shown in the neonatal period but can last into adulthood, both in structure, altered networks and function, also in the visual areas of the brain. (19–24) Visual impairments caused by adverse brain development are collectively referred to as cerebral visual impairment (CVI) and include both visual sensory impairment and deficient visual perception. CVI nowadays is the most frequent cause of visual impairment in children in developed countries, in contrast to the visual sequelae of ROP (25) , and is associated with deficiencies in the development of cognition and motor abilities. (11,26,27) CVI covers a wide range of deficits, from children merely suffering from spatial processing dysfunctions to deficits in object recognition and scene identification, and also cortically blind children, having no visual perception at all. (11)

In preterm born children, CVI is typically diagnosed in children with periventricular white matter disease, thus particularly in those born <32 weeks of gestation, although its prevalence is not exactly known. (28) However, CVI can also emerge in children without evident/overt brain pathology. The clinical profile of visual perceptive deficits can change during childhood. (11) Once CVI is suspected, regular follow-up of visual functioning is therefore advised.

Source

1. Stephenson T, Wright S, O'Connor A, Fielder A, Johnson A, Ratib S, et al. Children born weighing less than 1701 g: visual and cognitive outcomes at 11-14 years. *Arch Dis Child Fetal Neonatal Ed.* 2007 Jul;92(4):F265-270.
2. Holmström G, Larsson E. Long-term follow-up of visual functions in prematurely born children--a prospective population-based study up to 10 years of age. *J AAPOS Off Publ Am Assoc Pediatr Ophthalmol Strabismus.* 2008 Apr;12(2):157–62.
3. Stevens JP, Eames M, Kent A, Halket S, Holt D, Harvey D. Long term outcome of neonatal meningitis. *Arch Dis Child Fetal Neonatal Ed.* 2003 May;88(3):F179-184.
4. Azzopardi D, Strohm B, Marlow N, Brocklehurst P, Deierl A, Eddama O, et al. Effects of hypothermia for perinatal asphyxia on childhood outcomes. *N Engl J Med.* 2014 Jul 10;371(2):140–9.
5. Molloy CS, Di Battista AM, Anderson VA, Burnett A, Lee KJ, Roberts G, et al. The contribution of visual processing to academic achievement in adolescents born extremely preterm or extremely low birth weight. *Child Neuropsychol J Norm Abnorm Dev Child Adolesc.* 2017 Apr;23(3):361–79.
6. Rapin I. Dyscalculia and the Calculating Brain. *Pediatr Neurol.* 2016;61:11–20.
7. Downie ALS, Jakobson LS, Frisk V, Ushycky I. Periventricular brain injury, visual motion processing, and reading and spelling abilities in children who were extremely low birthweight. *J Int Neuropsychol Soc JINS.* 2003 Mar;9(3):440–9.
8. Beligere N, Perumalswamy V, Tandon M, Mittal A, Floora J, Vijayakumar B, et al. Retinopathy of prematurity and neurodevelopmental disabilities in premature infants. *Semin Fetal Neonatal Med.* 2015 Oct;20(5):346–53.

9. Chavda S, Hodge W, Si F, Diab K. Low-vision rehabilitation methods in children: a systematic review. *Can J Ophthalmol J Can Ophthalmol*. 2014 Jun;49(3):e71-73.
10. Holmström G, Larsson E. Outcome of retinopathy of prematurity. *Clin Perinatol*. 2013 Jun;40(2):311–21.
11. Ortibus EL, De Cock PP, Lagae LG. Visual perception in preterm children: what are we currently measuring? *Pediatr Neurol*. 2011 Jul;45(1):1–10.
12. Ricci D, Romeo DM, Gallini F, Groppo M, Cesarini L, Pisoni S, et al. Early visual assessment in preterm infants with and without brain lesions: correlation with visual and neurodevelopmental outcome at 12 months. *Early Hum Dev*. 2011 Mar;87(3):177–82.
13. Hellström A, Källén K, Carlsson B, Holmström G, Jakobsson P, Lundgren P, et al. Extreme prematurity, treated retinopathy, bronchopulmonary dysplasia and cerebral palsy are significant risk factors for ophthalmological abnormalities at 6.5 years of age. *Acta Paediatr Oslo Nor* 1992. 2018 May;107(5):811–21.
14. AMERICAN ACADEMY OF PEDIATRICS Section on Ophthalmology, AMERICAN ACADEMY OF OPHTHALMOLOGY, AMERICAN ASSOCIATION FOR PEDIATRIC OPHTHALMOLOGY AND STRABISMUS, AMERICAN ASSOCIATION OF CERTIFIED ORTHOPTISTS. Screening Examination of Premature Infants for Retinopathy of Prematurity. *PEDIATRICS*. 2013 Jan 1;131(1):189–95.
15. Geldof CJA, van Wassenaeer-Leemhuis AG, Dik M, Kok JH, Oosterlaan J. A functional approach to cerebral visual impairments in very preterm/very-low-birth-weight children. *Pediatr Res*. 2015 Aug;78(2):190–7.
16. Darlow BA, Elder MJ, Kimber B, Martin J, Horwood LJ. Vision in former very low birthweight young adults with and without retinopathy of prematurity compared with term born controls: the NZ 1986 VLBW follow-up study. *Br J Ophthalmol*. 2017 Dec 6;
17. Fierson WM, American Academy of Pediatrics Section on Ophthalmology, American Academy of Ophthalmology, American Association for Pediatric Ophthalmology and Strabismus, American Association of Certified Orthoptists. Screening examination of premature infants for retinopathy of prematurity. *Pediatrics*. 2013 Jan;131(1):189–95.
18. Raffa L, Aring E, Dahlgren J, Karlsson A-K, Andersson Grönlund M. Ophthalmological findings in relation to auxological data in moderate-to-late preterm preschool children. *Acta Ophthalmol (Copenh)*. 2015 Nov;93(7):635–41.
19. Brumbaugh JE, Conrad AL, Lee JK, DeVolder IJ, Zimmerman MB, Magnotta VA, et al. Altered brain function, structure, and developmental trajectory in children born late preterm. *Pediatr Res*. 2016;80(2):197–203.
20. Groppo M, Ricci D, Bassi L, Merchant N, Doria V, Arichi T, et al. Development of the optic radiations and visual function after premature birth. *Cortex*. 2014 Jul 1;56:30–7.
21. Kelly CE, Cheong JLY, Molloy C, Anderson PJ, Lee KJ, Burnett AC, et al. Neural Correlates of Impaired Vision in Adolescents Born Extremely Preterm and/or Extremely Low Birthweight. *PLOS ONE*. 2014 Mar 24;9(3):e93188.
22. Pavaine J, Young JM, Morgan BR, Shroff M, Raybaud C, Taylor MJ. Diffusion tensor imaging-based assessment of white matter tracts and visual-motor outcomes in very preterm neonates. *Neuroradiology*. 2016 Mar;58(3):301–10.
23. Ramenghi LA, Ricci D, Mercuri E, Groppo M, De Carli A, Ometto A, et al. Visual performance and brain structures in the developing brain of pre-term infants. *Early Hum Dev*. 2010 Jul;86 Suppl 1:73–5.
24. Thompson DK, Thai D, Kelly CE, Leemans A, Tournier J-D, Kean MJ, et al. Alterations in the optic radiations of very preterm children-Perinatal predictors and relationships with visual outcomes. *NeuroImage Clin*. 2014;4:145–53.

25. Bunce C, Xing W, Wormald R. Causes of blind and partial sight certifications in England and Wales: April 2007-March 2008. *Eye Lond Engl*. 2010 Nov;24(11):1692–9.
26. Geldof CJA, van Hus JWP, Jeukens-Visser M, Nollet F, Kok JH, Oosterlaan J, et al. Deficits in vision and visual attention associated with motor performance of very preterm/very low birth weight children. *Res Dev Disabil*. 2016 Jul;53–54:258–66.
27. Geldof CJA, van Wassenae AG, de Kieviet JF, Kok JH, Oosterlaan J. Visual perception and visual-motor integration in very preterm and/or very low birth weight children: a meta-analysis. *Res Dev Disabil*. 2012 Apr;33(2):726–36.
28. Dutton GN, McKillop ECA, Saidkasimova S. Visual problems as a result of brain damage in children. *Br J Ophthalmol*. 2006 Aug;90(8):932–3.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Ortibus E, Leemhuis AG et al., European Standards of Care for Newborn Health: Assessment of visual function. 2018.

Cognitive development

Wolke D, Leemhuis AG

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care) and parents

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Standardised cognitive assessment is conducted by two years of age and repeated at transition to school.

Rationale

The goal is to assess cognitive function and academic attainment in very preterm children.

Clinically significant adverse effects on general intelligence and specific executive functions and academic achievement have been shown as gestation decreases. (1,2) The risk of cognitive impairment is highest for extremely preterm births (1) or those with perinatal asphyxia, and most severe in those with additional social disadvantage. (3,4) The frequency of severe to moderate cognitive impairment ranges from 20% to over 30% in extremely preterm born children. (5–7) Moderate to severe cognitive impairments are apparent from assessments in the second year and show high stability across childhood and into adulthood. (8,9) In contrast, those who have mild impairment in cognitive function in standard tests can show both improvement and deterioration across childhood in functioning and require repeated monitoring. Cognitive disabilities can co-occur with other problems, such as motor and behaviour problems. They have adverse effects on schooling, and long-term effects on employment and independent living. (10) Cognitive impairments have high economic costs. (11)

There are no proven interventions leading to sustained cognitive improvements into school age for children with moderate to severe cognitive impairment. There is some evidence for improvement with intervention for those with mild cognitive impairment. (12–14) Interventions to increase quality of life and appropriate schooling are required for all affected by cognitive impairment.

Benefits

Short-term benefits

N/A

Long-term benefits

- Increased information on global cognitive functioning that is required for differential diagnosis (learning, inattention, autism, language, etc.) (15,16)
- Better informed parents (17,18)
- Appropriate intervention or management (17,18)
- Improved decision-making for schooling and learning support (17,18)
- Provided feedback to perinatal and neonatal services and healthcare officials (17,18)

- Provides endpoint for obstetric and neonatal high-quality trials (consensus)
- Reduced undue performance pressure on the child (consensus)
- Reduced risk of secondary mental health problems (consensus)
- Improved parent-child interaction adapted to cognitive ability (consensus)
- Improved academic outcome (consensus)
- Increased social integration and quality of life (consensus)
- Reduced social burden (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including cognitive assessments. (19)	A (High quality) B (High quality)	Patient information sheet
2. Parents receive standardised feedback about the results of the cognitive assessments in language that is accessible to them. (19)	A (High quality)	Parent feedback
3. Parents are asked to consent to use routine information from the school to include in outcome measures of cognitive impairment. (19)	A (High quality)	Completed consent
For healthcare professionals		
4. Country specific test norms are applied when interpreting the results of screening tests. (20)	A (High quality)	Guideline
5. A unit guideline on follow-up programme including cognitive assessment is adhered to by all healthcare professionals.	B (High quality)	Guideline
6. Training on standardised cognitive assessments, in which gestational age and first language are taken into account is attended by all responsible healthcare professionals. (8,21–23)	A (High quality) B (High quality)	Training documentation
For neonatal unit, hospital, and follow-up team		
7. A unit guideline on follow-up programme including cognitive assessment is available and regularly updated.	B (High quality)	Guideline

8. Training on standardised cognitive assessments is ensured.	B (High quality)	Training documentation
9. A follow-up programme after discharge including cognitive assessment is funded and supported. (19,24,25)	A (High quality) B (Moderate quality)	Audit report
10. Appropriate assessment rooms and facilities are available (hospital or provider). (19)	A (High quality) B (Moderate quality)	Audit report
11. Follow-up rates are continuously monitored. (19)	A (High quality) B (Moderate quality)	Audit report
12. Cognitive outcomes are used for staff feedback. (19)	A (High quality) B (Moderate quality)	Audit report
For health service		
13. A national guideline on follow-up programme including cognitive assessment is available and regularly updated.	B (High quality)	Guideline
14. A cognitive follow-up service is specified, funded and monitored.	B (High quality)	Audit report

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
• Cognitive follow-up at transition to secondary/high-school age is offered.	B (Moderate quality)
• Parents are supported by a case manager (see Follow-up & continuing care). (26)	A (High quality)
• Incentives to attend follow-up programmes are provided. (2,19,27)	A (High quality)
For healthcare professionals	
N/A	
For neonatal unit and follow-up team	
• Establish an integrated electronic system with cognitive follow-up provider to schedule follow-up visits.	B (Low quality)
For hospital and follow-up team	
• Dedicate an assessment facility.	B (Moderate quality)
For health service	
• Develop a national network for benchmarking of follow-up outcomes. (28,29)	A (High quality)
• Include follow-up information on an electronic healthcare card.	B (Low quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about the cognitive follow-up that is available, and the provider thereof.
- A service is initiated that uses parent reports using screening questionnaires. (30–32)

For healthcare professionals

- Institute a standard schedule of assessment.
- Attend training on standardised cognitive assessments.
- Coordinate follow-up with other healthcare providers.
- Identify an appropriate parent-completed cognitive screening questionnaire that has nationally established norms for use. (19)

For neonatal unit and follow-up team

- Develop and implement a unit guideline on follow-up programme including cognitive assessments.
- Develop information material on follow-up programme including cognitive assessments for parents.
- Establish a formal system of keeping track of families.
- Develop a structure of follow-up locally.

For hospital and follow-up team

- Support healthcare professionals to participate in training on standardised cognitive assessments.
- Provide space and resources for follow-up assessments in clinics or postal/online.

For health service

- Develop and implement a national guideline on cognitive assessments for target group.

Source

1. Wolke D, Strauss VY-C, Johnson S, Gilmore C, Marlow N, Jaekel J. Universal gestational age effects on cognitive and basic mathematic processing: 2 cohorts in 2 countries. *J Pediatr*. 2015 Jun;166(6):1410-1416-2.
2. MacKay DF, Smith GCS, Dobbie R, Pell JP. Gestational Age at Delivery and Special Educational Need: Retrospective Cohort Study of 407,503 Schoolchildren. Lau TK, editor. *PLoS Med*. 2010 Jun 8;7(6):e1000289.
3. Wolke D, Meyer R. Cognitive status, language attainment, and prereading skills of 6-year-old very preterm children and their peers: the Bavarian Longitudinal Study. *Dev Med Child Neurol*. 1999 Feb 1;41(2):94–109.
4. Eryigit Madzwamuse S, Baumann N, Jaekel J, Bartmann P, Wolke D. Neuro-cognitive performance of very preterm or very low birth weight adults at 26 years. *J Child Psychol Psychiatry*. 2015 Aug;56(8):857–64.
5. Wolke P. Preterm and Low Birth Weight Babies. In: Howlin P, Charman T, Ghaziuddin M, editors. *The SAGE Handbook of Developmental Disorders* [Internet]. 1st ed. London: SAGE; 2011 [cited 2018 May 16]. p. 497–527. Available from: <https://uk.sagepub.com/en-gb/eur/the-sage-handbook-of-developmental-disorders/book230988>
6. Twilhaar ES, Wade RM, de Kieviet JF, van Goudoever JB, van Elburg RM, Oosterlaan J. Cognitive Outcomes of Children Born Extremely or Very Preterm Since the 1990s and Associated Risk Factors: A Meta-analysis and Meta-regression. *JAMA Pediatr*. 2018 Apr 1;172(4):361–7.



7. Twilhaar ES, de Kieviet JF, Aarnoudse-Moens CS, van Elburg RM, Oosterlaan J. Academic performance of children born preterm: a meta-analysis and meta-regression. *Arch Dis Child Fetal Neonatal Ed.* 2017 Aug 28;
8. Breeman LD, Jaekel J, Baumann N, Bartmann P, Wolke D. Preterm Cognitive Function Into Adulthood. *Pediatrics.* 2015 Sep;136(3):415–23.
9. Linsell L, Johnson S, Wolke D, O'Reilly H, Morris JK, Kurinczuk JJ, et al. Cognitive trajectories from infancy to early adulthood following birth before 26 weeks of gestation: a prospective, population-based cohort study. *Arch Dis Child.* 2018 Apr;103(4):363–70.
10. Basten M, Jaekel J, Johnson S, Gilmore C, Wolke D. Preterm Birth and Adult Wealth: Mathematics Skills Count. *Psychol Sci.* 2015 Oct;26(10):1608–19.
11. Petrou S, Johnson S, Wolke D, Marlow N. The association between neurodevelopmental disability and economic outcomes during mid-childhood. *Child Care Health Dev.* 2013 May;39(3):345–57.
12. Orton J, Spittle A, Doyle L, Anderson P, Boyd R. Do early intervention programmes improve cognitive and motor outcomes for preterm infants after discharge? A systematic review. *Dev Med Child Neurol.* 2009 Nov;51(11):851–9.
13. Spittle A. Early intervention cognitive effects not sustained past preschool. *J Pediatr.* 2015 Mar;166(3):779.
14. van Wassenae-Leemhuis AG, Jeukens-Visser M, van Hus JWP, Meijssen D, Wolf M-J, Kok JH, et al. Rethinking preventive post-discharge intervention programmes for very preterm infants and their parents. *Dev Med Child Neurol.* 2016 Mar;58:67–73.
15. O'Hare A, Bremner L. Management of developmental speech and language disorders: Part 1. *Arch Dis Child.* 2016 Mar;101(3):272–7.
16. NICE Pathways. Developmental follow-up of children and young people born preterm overview. National Institute for Health and Clinical Excellence; 2018.
17. Doyle LW, Anderson PJ, Battin M, Bowen JR, Brown N, Callanan C, et al. Long term follow up of high risk children: who, why and how? *BMC Pediatr.* 2014 Nov 17;14:279.
18. Johnson S, Gilmore C, Gallimore I, Jaekel J, Wolke D. The long-term consequences of preterm birth: what do teachers know? *Dev Med Child Neurol.* 2015 Jun;57(6):571–7.
19. NICE guideline. Developmental follow-up of children and young people born preterm (NG 72) [Internet]. National Institute for Health and Clinical Excellence; 2017. Available from: <https://www.nice.org.uk/guidance/ng72>
20. Westera JJ, Houtzager BA, Overdiek B, van Wassenae AG. Applying Dutch and US versions of the BSID-II in Dutch children born preterm leads to different outcomes. *Dev Med Child Neurol.* 2008 Jun;50(6):445–9.
21. Johnson S, Wolke D, Marlow N. Outcome monitoring in preterm populations - Measures and methods. *Z Für Psychol J Psychol.* 2008 Jan 1;216(3):135–46.
22. Drotar D, Stancin T, Dworkin PH, Sices L, Wood S. Selecting developmental surveillance and screening tools. *Pediatr Rev.* 2008 Oct;29(10):e52-58.
23. van Veen S, Aarnoudse-Moens CSH, van Kaam AH, Oosterlaan J, van Wassenae-Leemhuis AG. Consequences of Correcting Intelligence Quotient for Prematurity at Age 5 Years. *J Pediatr.* 2016 Jun;173:90–5.
24. Hille ETM, Elbertse L, Gravenhorst JB, Brand R, Verloove-Vanhorick SP, Dutch POPS-19 Collaborative Study Group. Nonresponse bias in a follow-up study of 19-year-old adolescents born as preterm infants. *Pediatrics.* 2005 Nov;116(5):e662-666.



25. Wolke D, Söhne B, Ohrt B, Riegel K. Follow-up of preterm children: important to document dropouts. *The Lancet*. 1995 Feb 18;345(8947):447.
26. Hüning BM, Reimann M, Beerenberg U, Stein A, Schmidt A, Felderhoff-Müser U. Establishment of a family-centred care programme with follow-up home visits: implications for clinical care and economic characteristics. *Klin Pädiatr*. 2012 Nov;224(7):431–6.
27. Bassani DG, Arora P, Wazny K, Gaffey MF, Lenters L, Bhutta ZA. Financial incentives and coverage of child health interventions: a systematic review and meta-analysis. *BMC Public Health*. 2013;13 Suppl 3:S30.
28. Wang CJ, McGlynn EA, Brook RH, Leonard CH, Piecuch RE, Hsueh SI, et al. Quality-of-care indicators for the neurodevelopmental follow-up of very low birth weight children: results of an expert panel process. *Pediatrics*. 2006 Jun;117(6):2080–92.
29. Mercier CE, Dunn MS, Ferrelli KR, Howard DB, Soll RF, Vermont Oxford Network ELBW Infant Follow-Up Study Group. Neurodevelopmental outcome of extremely low birth weight infants from the Vermont Oxford network: 1998-2003. *Neonatology*. 2010 Jun;97(4):329–38.
30. Marks K, Hix-Small H, Clark K, Newman J. Lowering developmental screening thresholds and raising quality improvement for preterm children. *Pediatrics*. 2009 Jun;123(6):1516–23.
31. Hix-Small H, Marks K, Squires J, Nickel R. Impact of implementing developmental screening at 12 and 24 months in a pediatric practice. *Pediatrics*. 2007 Aug;120(2):381–9.
32. Johnson S, Wolke D, Marlow N, Preterm Infant Parenting Study Group. Developmental assessment of preterm infants at 2 years: validity of parent reports. *Dev Med Child Neurol*. 2008 Jan;50(1):58–62.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Wolke D, Leemhuis AG, European Standards of Care for Newborn Health: Cognitive development; 2018.

Communication, speech, and language

Sansavini A, Bosch L, Wolke D, Leemhuis AG

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care), parents, and families

User group

Healthcare professionals, neonatal units, hospitals, health services, and follow-up services

Statement of Standard

Standardised assessment of communication, speech, and language development is conducted by two years of age and repeated at transition to school.

Rationale

The goal is to assess and evaluate communication, speech and language development and guide pathways for parents and educational management in case of impairment.

Clinically significant long-term adverse effects of preterm birth have been shown for speech and language. (1–4) Biomedical risk factors, such as brain injury, extremely low gestational age, intrauterine growth restriction, and bronchopulmonary dysplasia (5–7), as well as social risk factors, such as low maternal education, lack of parenting responsiveness, and ethnical minority status (4,6,8), increase risk. Association with delays in other domains is common (30%) and very frequent in case of neurological damage (9), motor or neurosensory impairments. (10)

Weaknesses in early basic cognitive, communication and motor skills affect later language abilities. (5,6,11,12) In particular, gestural, and vocal production are less advanced in very preterm infants and predictive of language skills at two years. (6,13–15) Joint attention is weaker in very preterm infants but modulated by maternal behaviour. (16,17) Early feeding problems may contribute to oral, sensory, motor, and speech dysfunctions. (18) Delays in lexicon, grammar, and phonological skills are detectable at two-three years (2,5,19–23) and become more evident during preschool and school age when also pragmatic difficulties appear. (1,2,24–26)

Delays in phonological awareness, a precursor of literacy and school achievement, have been identified in very preterm infants at six and eight years. (24,27) Language difficulties impact learning and academic achievement as well as social interactions (28) and are associated with high individual and societal costs.

Benefits

Short-term benefits

N/A

Long-term benefits

- Improved information on communication, speech, and language functioning that is required for diagnosis of communication, speech, and language impairment and for differential diagnosis (autism, etc.) (4,16)
- Provides feedback to parents and/or main caretakers (4,16)
- Improved planning of appropriate intervention or management (4,16)
- Improved decision making for schooling and learning support (4,16)

- Provides feedback to perinatal and neonatal services and healthcare officials (4,16)
- Provides an endpoint for obstetric and neonatal high-quality trials (4,16)
- Reduced undue performance pressure on the child (consensus)
- Reduced risk of secondary mental health problems (consensus)
- Improved parent-child interaction and adaptation to the child language skills (4,16)
- Improved reading and writing skills and academic outcomes (consensus)
- Increased social integration and quality of life (consensus)
- Reduced social burden and social costs (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including speech and language assessments.	B (High quality)	Patient information sheet
2. Parents receive standardised feedback in language that is accessible to them.	B (High quality)	Parent feedback
3. Parents are encouraged to communicate with their infant and expose them to language during family-centered care (see Infant- & family-centred developmental care and Follow-up & continuing care). (4,29)	B (High quality)	Parent feedback
For healthcare professionals		
4. A guideline on standardised follow-up programme including speech and language assessments is adhered to by all healthcare professionals.	B (High quality)	Guideline
5. Country specific test norms are applied when interpreting the results of screening tests. (30)	A (High quality)	Training documentation
6. Training on standardised speech and language assessments, in which gestational age and first language are taken into account is attended by all responsible healthcare professionals. (1–4,7)	A (High quality) B (High quality)	Training documentation
7. The predominant language at home (main caretaker), is noted in the assessment. (31,32)	A (High quality)	Parent feedback, training documentation

For neonatal unit, hospital, and follow-up team		
8. A unit guideline on standardised follow-up programme including speech and language assessments is available and regularly updated.	B (High quality)	Guideline
9. Speech and language follow-up programme after discharge is funded and supported.	B (Moderate quality)	Audit report
10. Appropriate assessment rooms and facilities are available (hospital or provider).	B (Moderate quality)	Audit report
11. Follow-up rates are continuously monitored. (33,34)	A (High quality) B (Moderate quality)	Audit report
12. Speech and language outcomes are used for healthcare professional feedback.	B (Moderate quality)	Training documentation
13. Training on standardised speech and language assessments is ensured.	B (High quality)	Training documentation
For health service		
14. A national guideline on standardised follow-up programme including speech and language assessments is available and regularly updated.	B (High quality)	Guideline
15. A follow-up service including speech and language assessments is funded and monitored.	B (High quality)	Audit report

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
• Parents are supported by a case manager (see Follow-up & continuing care).	B (Moderate quality)
• Parents are provided with incentives to attend follow-up for those who are socially disadvantaged.	B (Moderate quality)
• Families receive support in communication and language strategies.	B (Moderate quality)
For healthcare professionals	
N/A	
For neonatal unit, hospital, and follow-up team	
• Establish an integrated electronic system with communication, speech, and language follow-up provider to schedule follow-up visits.	B (Moderate quality)

- Provide a dedicated assessment facility. B (Moderate quality)
 - Support feeding, functioning or communication by physiotherapists and speech therapists. B (Moderate quality)
- For health service**
- Develop a national network for benchmarking of follow-up quality. B (Moderate quality)
 - Provide common observation and clinical tools for identifying early indexes of risk of language delay in preterm children. B (Moderate quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about follow-up programme including speech and language assessments.
- A service is initiated that uses parent reports using screening questionnaires. (35–42)

For healthcare professionals

- Attend training on standardised speech and language assessments.
- Institute a standard schedule of assessment.
- Establish communication with other healthcare institutions providing follow-up care.

For neonatal unit, hospital, and follow-up team

- Develop and implement a unit guideline on standardised speech and language assessments.
- Develop information material on follow-up programme including speech and language assessments for parents.
- Support healthcare professionals to participate in training on standardised speech and language assessments.
- Provide space and resources for follow-up assessments in clinics or postal/online.

For health service

- Develop and implement a national guideline on standardised follow-up programme including speech and language.

Source

1. Barre N, Morgan A, Doyle LW, Anderson PJ. Language abilities in children who were very preterm and/or very low birth weight: a meta-analysis. *J Pediatr*. 2011 May;158(5):766–774.e1.
2. van Noort-van der Spek IL, Franken M-CJP, Weisglas-Kuperus N. Language functions in preterm-born children: a systematic review and meta-analysis. *Pediatrics*. 2012 Apr;129(4):745–54.
3. Sansavini A, Guarini A, Caselli MC. Preterm birth: neuropsychological profiles and atypical developmental pathways. *Dev Disabil Res Rev*. 2011;17(2):102–13.
4. Vohr B. Speech and language outcomes of very preterm infants. *Semin Fetal Neonatal Med*. 2014 Apr;19(2):78–83.
5. Sansavini A, Pentimonti J, Justice L, Guarini A, Savini S, Alessandrini R, et al. Language, motor and cognitive development of extremely preterm children: modeling individual growth trajectories over the first three years of life. *J Commun Disord*. 2014 Jun;49:55–68.

6. Sansavini A, Guarini A, Savini S, Broccoli S, Justice L, Alessandroni R, et al. Longitudinal trajectories of gestural and linguistic abilities in very preterm infants in the second year of life. *Neuropsychologia*. 2011 Nov 1;49(13):3677–88.
7. Wolke D, Samara M, Bracewell M, Marlow N, EPICure Study Group. Specific language difficulties and school achievement in children born at 25 weeks of gestation or less. *J Pediatr*. 2008 Feb;152(2):256–62.
8. Bozzette M. A Review of Research on Premature Infant-Mother Interaction. *Newborn Infant Nurs Rev*. 2007 Mar 1;7(1):49–55.
9. Woodward LJ, Moor S, Hood KM, Champion PR, Foster-Cohen S, Inder TE, et al. Very preterm children show impairments across multiple neurodevelopmental domains by age 4 years. *Arch Dis Child Fetal Neonatal Ed*. 2009 Sep;94(5):F339–344.
10. Mwaniki MK, Atieno M, Lawn JE, Newton CRJC. Long-term neurodevelopmental outcomes after intrauterine and neonatal insults: a systematic review. *Lancet Lond Engl*. 2012 Feb 4;379(9814):445–52.
11. Rose SA, Feldman JF, Jankowski JJ. A cognitive approach to the development of early language. *Child Dev*. 2009 Feb;80(1):134–50.
12. Rose SA, Feldman JF, Jankowski JJ. Modeling a cascade of effects: the role of speed and executive functioning in preterm/full-term differences in academic achievement. *Dev Sci*. 2011 Sep;14(5):1161–75.
13. Benassi E, Savini S, Iverson JM, Guarini A, Caselli MC, Alessandroni R, et al. Early communicative behaviors and their relationship to motor skills in extremely preterm infants. *Res Dev Disabil*. 2016 Jan;48:132–44.
14. Stolt S, Mäkilä A-M, Matomäki J, Lehtonen L, Lapinleimu H, Haataja L. The development and predictive value of gestures in very-low-birth-weight children: a longitudinal study. *Int J Speech Lang Pathol*. 2014 Apr;16(2):121–31.
15. Rvachew S, Creighton D, Feldman N, Sauve R. Vocal development of infants with very low birth weight. *Clin Linguist Phon*. 2005 Jun 1;19(4):275–94.
16. Landry SH, Garner PW, Swank PR, Baldwin CD. Effects of Maternal Scaffolding During Joint Toy Play With Preterm and Full-Term Infants. *Merrill-Palmer Q*. 1996;42(2):177–99.
17. Sansavini A, Zavagli V, Guarini A, Savini S, Alessandroni R, Faldella G. Dyadic co-regulation, affective intensity and infant's development at 12 months: A comparison among extremely preterm and full-term dyads. *Infant Behav Dev*. 2015 Aug 1;40:29–40.
18. Sanchez K, Spittle AJ, Slattery JM, Morgan AT. Oromotor Feeding in Children Born Before 30 Weeks' Gestation and Term-Born Peers at 12 Months' Corrected Age. *J Pediatr*. 2016 Nov;178:113–118.e1.
19. Sansavini A, Guarini A, Justice LM, Savini S, Broccoli S, Alessandroni R, et al. Does preterm birth increase a child's risk for language impairment? *Early Hum Dev*. 2010 Dec;86(12):765–72.
20. Stolt S, Haataja L, Lapinleimu H, Lehtonen L. The early lexical development and its predictive value to language skills at 2 years in very-low-birth-weight children. *J Commun Disord*. 2009 Apr;42(2):107–23.
21. Foster-Cohen S, Edgin JO, Champion PR, Woodward LJ. Early delayed language development in very preterm infants: evidence from the MacArthur-Bates CDI. *J Child Lang*. 2007 Aug;34(3):655–75.
22. D'Odorico L, Majorano M, Fasolo M, Salerni N, Suttora C. Characteristics of phonological development as a risk factor for language development in Italian-speaking pre-term children: A longitudinal study. *Clin Linguist Phon*. 2011 Jan;25(1):53–65.



23. Ortiz-Mantilla S, Choudhury N, Leever H, Benasich AA. Understanding language and cognitive deficits in very low birth weight children. *Dev Psychobiol.* 2008 Mar;50(2):107–26.
24. Guarini A, Sansavini A, Fabbri C, Savini S, Alessandrini R, Faldella G, et al. Long-term effects of preterm birth on language and literacy at eight years. *J Child Lang.* 2010 Sep;37(4):865–85.
25. Guarini A, Marini A, Savini S, Alessandrini R, Faldella G, Sansavini A. Linguistic features in children born very preterm at preschool age. *Dev Med Child Neurol.* 2016;58(9):949–56.
26. Wolke D, Dipl-Psych; RM. Cognitive status, language attainment, and prereading skills of 6-year-old very preterm children and their peers: the Bavarian Longitudinal Study. *Dev Med Child Neurol.* 1999 Feb 1;41(2):94–109.
27. Guarini A, Sansavini A, Fabbri C, Alessandrini R, Faldella G, Karmiloff-Smith A. Reconsidering the impact of preterm birth on language outcome. *Early Hum Dev.* 2009 Oct;85(10):639–45.
28. St Clair MC, Pickles A, Durkin K, Conti-Ramsden G. A longitudinal study of behavioral, emotional and social difficulties in individuals with a history of specific language impairment (SLI). *J Commun Disord.* 2011 Apr;44(2):186–99.
29. Pineda R, Durant P, Mathur A, Inder T, Wallendorf M, Schlaggar BL. Auditory Exposure in the Neonatal Intensive Care Unit: Room Type and Other Predictors. *J Pediatr.* 2017 Apr;183:56–66.e3.
30. Westera JJ, Houtzager BA, Overdiek B, van Wassenae AG. Applying Dutch and US versions of the BSID-II in Dutch children born preterm leads to different outcomes. *Dev Med Child Neurol.* 2008 Jun;50(6):445–9.
31. DeAnda S, Bosch L, Poulin-Dubois D, Zesiger P, Friend M. The Language Exposure Assessment Tool: Quantifying Language Exposure in Infants and Children. *J Speech Lang Hear Res JSLHR.* 2016 Dec 1;59(6):1346–56.
32. Hoff E, Core C, Place S, Rumiche R, Señor M, Parra M. Dual language exposure and early bilingual development. *J Child Lang.* 2012 Jan;39(1):1–27.
33. Hille ETM, Elbertse L, Gravenhorst JB, Brand R, Verloove-Vanhorick SP, Dutch POPS-19 Collaborative Study Group. Nonresponse bias in a follow-up study of 19-year-old adolescents born as preterm infants. *Pediatrics.* 2005 Nov;116(5):e662–666.
34. Wolke D, Söhne B, Ohrt B, Riegel K. Follow-up of preterm children: important to document dropouts. *The Lancet.* 1995 Feb 18;345(8947):447.
35. Fenson L, Marchman V, Thal D, Dale P, Reznick J, Bates E. MacArthur-Bates Communicative Development Inventories: User's guide and technical manual. 2nd ed. Baltimore, MD: Brookes; 2007.
36. Johnson S, Wolke D, Marlow N, Preterm Infant Parenting Study Group. Developmental assessment of preterm infants at 2 years: validity of parent reports. *Dev Med Child Neurol.* 2008 Jan;50(1):58–62.
37. Cuttini M, Ferrante P, Mirante N, Chiandotto V, Fertz M, Dall'Oglio AM, et al. Cognitive assessment of very preterm infants at 2-year corrected age: performance of the Italian version of the PARCA-R parent questionnaire. *Early Hum Dev.* 2012 Mar;88(3):159–63.
38. Hix-Small H, Marks K, Squires J, Nickel R. Impact of implementing developmental screening at 12 and 24 months in a pediatric practice. *Pediatrics.* 2007 Aug;120(2):381–9.
39. Marks K, Hix-Small H, Clark K, Newman J. Lowering developmental screening thresholds and raising quality improvement for preterm children. *Pediatrics.* 2009 Jun;123(6):1516–23.
40. Schonhaut L, Armijo I, Schönstedt M, Alvarez J, Cordero M. Validity of the Ages and Stages Questionnaires in Term and Preterm Infants. *Pediatrics.* 2013 May 1;131(5):e1468–74.



41. Flamant C, Branger B, Tich SNT, Rochebrochard E de L, Savagner C, Berlie I, et al. Parent-Completed Developmental Screening in Premature Children: A Valid Tool for Follow-Up Programs. PLOS ONE. 2011 May 26;6(5):e20004.
42. Squires J, Bricker D, Potter L. Revision of a parent-completed development screening tool: Ages and Stages Questionnaires. J Pediatr Psychol. 1997 Jun;22(3):313–28.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Sansavini A, Bosch L et al., European Standards of Care for Newborn Health: Communication, speech, and language. 2018.



Coordination and integration of care after discharge home

van Kempen A, van Steenbrugge G, Leemhuis AG, Wolke D

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care), parents, and families

User group

Healthcare professionals, neonatal units, hospitals, health services, and follow-up teams

Statement of standard

Parents receive comprehensive and integrated care for their high-risk infant after discharge home.

Rationale

Care programmes for high-risk infants may involve a range of professionals and disciplines. (1,2) Growth, feeding and development are addressed in all infants, and interventions, such as physiotherapy, (preverbal) speech therapy, dietetics, occupational therapy, or psychological support are often instituted. (3–9) Such follow-on care must also integrate with primary, secondary, and tertiary services, such as family physicians, paediatricians, neonatologists, and other healthcare professionals. Multidisciplinary collaboration and coordination of care between professionals in different healthcare settings is necessary to prevent families falling through gaps in care and to avoid needless treatment duplication. (10–13) An integrated schedule of follow-up and aftercare visits will decrease the burden of unnecessary visits.

Timely communication of the medical record is a prerequisite for coordinated care. (10,11,14) Digital systems can facilitate this. (15) Case managers will provide coordination and continuity of care and treatment goals, and facilitate access to appropriate resources. (14,16,17) As there is no uniform approach in follow-up and aftercare programmes (14,18), local guidelines need to be developed about the assignment of tasks between healthcare professionals. The focus of care changes over time from medical problems, feeding and growth, to later development, behaviour, and schooling. Case managers with different backgrounds may be required over time. Patient-centred care, close parental engagement, and shared decision making are essential in infants with complex needs. Parents are the primary caregivers and advocate for their child; they should be included as equal partners in the multidisciplinary team. (19–24)

Benefits

Short-term benefits

N/A

Long-term benefits

- Continued care (25)
- Improved post-discharge multidisciplinary care, including positive parenting interventions and other home-visits (13,26,27)
- Reduced unplanned emergency room visits and readmissions (26)
- Improved parental engagement and satisfaction (16,27)
- Improved communication between healthcare professionals involved in the care of the child (28)

- Improved access to, and use of, health and developmental services (10,16)
- Early identification of healthcare needs, e.g. need for developmental support (25)
- Improved parental advocacy skills, i.e. the parents' ability to speak up for their child (29)
- Reduced healthcare costs (30)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals about the importance of adequate healthcare for their infant, which includes attendance in follow-up programmes and the role of the case manager. (31,32)	A (Low quality) B (High quality)	Clinical records, patient information sheet
2. Parents, as the primary caregivers are supported by a professional case manager for overview and coordination of the plan for follow-on care. (23,28,33,34)	A (Low quality) B (High quality)	Audit report, parent feedback, patient information sheet
For healthcare professionals		
3. A unit guideline on follow-up management including the support of the parents by a case manager is adhered to by all healthcare professionals.	B (High quality)	Guideline
4. Training on specific needs of high-risk infants in general and follow-up management is attended by all healthcare professionals and case managers to facilitate care for individual infants and families.	B (High quality)	Training documentation
5. Case managers work with parents to facilitate parental engagement and decision making during follow-up care. (5,12,22,28,33–36)	A (Low quality) B (High quality)	Guideline, parent feedback
6. Information exchange between all involved healthcare professionals and parents is documented and monitored. (3,10,11,14)	B (Moderate quality)	Clinical records
7. Contacts as part of the local follow-up programme are planned and coordinated, and meet the specific	B (High quality)	Guideline, parent feedback

needs of the individual infant and family. (3–9)

For neonatal unit and follow-up team

8. A unit guideline on follow-up programme including the support of the parents by a case manager is available and regularly updated. (3–9)	B (High quality)	Guideline
---	------------------	-----------

For hospital and follow-up team

9. Training on specific needs of high-risk infants in general, and follow-up management is ensured.	B (High quality)	Training documentation
10. Appropriate resources and facilities for follow-up programme are provided to optimise coordination of healthcare professional input for family.	B (High quality)	Audit report

For health service

11. A national guideline on follow-up management including the support of the parents by a case manager is available and regularly updated.	B (High 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 follow-up team

• Develop the accessibility of follow-up services, using e-health technology to support parents and health professionals. (35,36)	A (Low quality) B (Moderate quality)
• Develop the most effective ways of communication between multidisciplinary team members and parents.	B (Moderate quality)

For hospital and follow-up team

N/A

For health service

• Improve digital communication, integrating patient files and databases to facilitate timely handover, and ongoing care. (15)	A (Low quality) B (Moderate quality)
--	---

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about the follow-up care that is available.
- Parents are given contact details for questions about the infant's follow-up healthcare.

For healthcare professionals

- Attend training to improve knowledge on the specific needs of high-risk infants in general and especially training on case management.
- Ensure timely exchange of medical information and relevant family circumstances.

For neonatal unit and follow-up team

- Develop and implement a unit guideline for case management that starts prior to discharge.
- Develop information material about the available follow-up programme for parents.
- Develop a (paper) form to structure handover of essential medical information.

For hospital and follow-up team

- Support healthcare professionals and case managers to participate in training and education programmes to improve knowledge on the specific needs of the high-risk infants including case management.

For health service

- Develop and implement a national guideline for case management that starts prior to discharge.
- Develop and implement a policy to enable multi-disciplinary collaboration, synchronisation and necessary exchange of medical records between healthcare professionals at different levels in infant care.

Source

1. Doyle LW, Anderson PJ, Battin M, Bowen JR, Brown N, Callanan C, et al. Long term follow up of high risk children: who, why and how? *BMC Pediatr*. 2014 Nov 17;14:279.
2. Tang BG, Feldman HM, Huffman LC, Kagawa KJ, Gould JB. Missed opportunities in the referral of high-risk infants to early intervention. *Pediatrics*. 2012 Jun;129(6):1027–34.
3. Jefferies AL, Canadian Paediatric Society, Fetus and Newborn Committee. Going home: Facilitating discharge of the preterm infant. *Paediatr Child Health*. 2014 Jan;19(1):31–42.
4. Premature newborn care - Follow up. *BMJ Best Practice* [Internet]. 2017 [cited 2017 Mar 5]. Available from: <http://bestpractice.bmj.com/best-practice/monograph/671/follow-up/recommendations.html>
5. Van der Pal S, Heerdink N, Kamphuis M, Pols MA. [Dutch Preventive Youth Health Care Service guideline on children born too early and/or too small for gestational age]. *Ned Tijdschr Geneeskd*. 2014;158:A6745–A6745.
6. Phillips RM, Goldstein M, Hougland K, Nandyal R, Pizzica A, Santa-Donato A, et al. Multidisciplinary guidelines for the care of late preterm infants. *J Perinatol*. 2013 Jul;33(Suppl 2):S5–22.
7. LaHood A, Bryant C. Outpatient Care of the Premature Infant. *Am Fam Physician*. 2007 Oct 15;76(8):1159–64.

8. National Perinatal Association. Multidisciplinary Guidelines for the Care of Late Preterm Infants. [Internet]. Lonedell, MO; [cited 2017 Mar 5]. Available from: <http://www.nationalperinatal.org/Resources/LatePretermGuidelinesNPA.pdf>
9. NICE guideline. Developmental follow-up of children and young people born preterm (NG 72) [Internet]. National Institute for Health and Clinical Excellence; 2017. Available from: <https://www.nice.org.uk/guidance/ng72>
10. Law J, McCann D, O'May F. Managing change in the care of children with complex needs: healthcare providers' perspectives. *J Adv Nurs*. 2011 Dec;67(12):2551–60.
11. Woods S, Riley P. A role for community health care providers in neonatal follow-up. *Paediatr Child Health*. 2006 May;11(5):301–2.
12. Andrews B, Myers P, Osterhout P, Pellerite M, Zimmerman A, Msall M. NICU Follow-up Care: The Developmental and Advocacy Perspectives. *NeoReviews*. 2014 Aug 1;15(8):e336–43.
13. Moyer VA, Singh H, Finkel KL, Giardino AP. Transitions from neonatal intensive care unit to ambulatory care: description and evaluation of the proactive risk assessment process. *Qual Saf Health Care*. 2010 Oct;19 Suppl 3:i26–30.
14. Sauve R, Lee SK. Neonatal follow-up programs and follow-up studies: Historical and current perspectives. *Paediatr Child Health*. 2006 May;11(5):267–70.
15. Palma JP, Sharek PJ, Longhurst CA. Impact of electronic medical record integration of a handoff tool on sign-out in a newborn intensive care unit. *J Perinatol Off J Calif Perinat Assoc*. 2011 May;31(5):311–7.
16. Gillette Y, Hansen NB, Robinson JL, Kirkpatrick K, Grywalski R. Hospital-based case management for medically fragile infants: results of a randomized trial. *Patient Educ Couns*. 1991 Feb;17(1):59–70.
17. Gillette Y, Hansen NB, Robinson JL, Kirkpatrick K, Grywalski R. Hospital-based case management for medically fragile infants: program design. *Patient Educ Couns*. 1991 Feb;17(1):49–58.
18. Kuppala VS, Tabangin M, Haberman B, Steichen J, Yolton K. Current state of high-risk infant follow-up care in the United States: results of a national survey of academic follow-up programs. *J Perinatol Off J Calif Perinat Assoc*. 2012 Apr;32(4):293–8.
19. Craig JW, Glick C, Phillips R, Hall SL, Smith J, Browne J. Recommendations for involving the family in developmental care of the NICU baby. *J Perinatol*. 2015 Dec;35(Suppl 1):S5–8.
20. O'Brien K, Bracht M, Robson K, Ye XY, Mirea L, Cruz M, et al. Evaluation of the Family Integrated Care model of neonatal intensive care: a cluster randomized controlled trial in Canada and Australia. *BMC Pediatr*. 2015 Dec 15;15:210.
21. Lee SK, O'Brien K. Parents as primary caregivers in the neonatal intensive care unit. *CMAJ Can Med Assoc J J Assoc Medicales Can*. 2014 Aug 5;186(11):845–7.
22. Holmström I, Röing M. The relation between patient-centeredness and patient empowerment: a discussion on concepts. *Patient Educ Couns*. 2010 May;79(2):167–72.
23. Corlett J, Twycross A. Negotiation of parental roles within family-centred care: a review of the research. *J Clin Nurs*. 2006 Oct;15(10):1308–16.
24. Saigal S, Stoskopf BL, Feeny D, Furlong W, Burrows E, Rosenbaum PL, et al. Differences in preferences for neonatal outcomes among health care professionals, parents, and adolescents. *JAMA*. 1999 Jun 2;281(21):1991–7.
25. Smith LD. Continuity of care through nursing case management of the chronically ill child. *Clin Nurse Spec CNS*. 1994 Mar;8(2):65–8.

26. Ahmadpour-Kacho M, Pasha YZ, Aliabadi BM. Outcomes of very-low-birthweight infants after discharge with a discharge weight of 1500 grams. *Pediatr Int Off J Jpn Pediatr Soc.* 2012 Apr;54(2):196–9.
27. Moyer VA, Papile L-A, Eichenwald E, Giardino AP, Khan MM, Singh H. An intervention to improve transitions from NICU to ambulatory care: quasi-experimental study. *BMJ Qual Saf.* 2014 Dec;23(12):e3.
28. Opel DJ. A Push for Progress With Shared Decision-making in Pediatrics. *Pediatrics.* 2017;139(2).
29. Alsem MW, van Meeteren KM, Verhoef M, Schmitz MJWM, Jongmans MJ, Meily-Visser JMA, et al. Co-creation of a digital tool for the empowerment of parents of children with physical disabilities. *Res Involv Engagem.* 2017;3:26.
30. Thompson DG, Maringer M. Using case management to improve care delivery in the NICU. *MCN Am J Matern Child Nurs.* 1995 Oct;20(5):257–60.
31. Ballantyne M, Stevens B, Guttmann A, Willan AR, Rosenbaum P. Maternal and infant predictors of attendance at Neonatal Follow-Up programmes. *Child Care Health Dev.* 2014 Mar;40(2):250–8.
32. Ballantyne M, Stevens B, Guttmann A, Willan AR, Rosenbaum P. Transition to neonatal follow-up programs: is attendance a problem? *J Perinat Neonatal Nurs.* 2012 Mar;26(1):90–8.
33. Little AA, Kamholz K, Corwin BK, Barrero-Castillero A, Wang CJ. Understanding Barriers to Early Intervention Services for Preterm Infants: Lessons From Two States. *Acad Pediatr.* 2015 Aug;15(4):430–8.
34. Vonderheid SC, Rankin K, Norr K, Vasa R, Hill S, White-Traut R. Health Care Use Outcomes of an Integrated Hospital-to-Home Mother-Preterm Infant Intervention. *J Obstet Gynecol Neonatal Nurs JOGNN.* 2016 Oct;45(5):625–38.
35. Lopez GL, Anderson KH, Feutchinger J. Transition of premature infants from hospital to home life. *Neonatal Netw NN.* 2012 Aug;31(4):207–14.
36. Lindberg B, Axelsson K, Ohrling K. Experience with videoconferencing between a neonatal unit and the families' home from the perspective of certified paediatric nurses. *J Telemed Telecare.* 2009;15(6):275–80.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, van Kempen A, van Steenbrugge G et al., European Standards of Care for Newborn Health: Coordination and integration of care after discharge home; 2018.



Healthy lifestyle and cardiovascular risk factors

Kajantie E, Leemhuis AG, Wolke D

Target group

Children and adults born very preterm or those with risk factors (see preamble Follow-up & continuing care), parents, and families

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Key cardiometabolic risk factors (in particular blood pressure, abdominal obesity and physical inactivity) are monitored from childhood to adult life.

Rationale

Children and adults born very preterm are likely to be at increased risk of common late-life diseases, such as coronary heart disease, high blood pressure, stroke, type 2 diabetes, and impaired glucose regulation which jointly are referred to as “cardiometabolic disease”. (1–5) Some studies also point to increased abdominal fat, although evidence is less certain. (6) Importantly, those born preterm seem to undertake less physical activity (7) and are less fit (8), comprising a potential target for secondary prevention.

In addition to cardiometabolic risk factors, children and adults may have reduced lung function (see separate standard) (9) and reduced bone mineral density. (10) Increasing physical activity and fitness carries benefits also in terms of lung and bone health.

These risks highlight the need of promotion of healthy lifestyle and vigilance in detecting individuals among whom specific risk factors attain levels that may warrant intervention. Promotion of healthy lifestyle is likely to benefit the whole family.

There are no published studies assessing the efficacy of preventive measures specifically in children born preterm. However, there are evidence-based guidelines on healthy lifestyle for the general population and on detection of high-risk individuals and prevention based on individual risk factors.

Long-term outcomes in children and adults born preterm are currently under intensive research and have been highlighted as an important research topic by agencies such as the US National Institutes of Health. (11) This research is likely to provide new scientific evidence to support the recommendations.

Many of the health benefits considered in this recommendation are best achieved through “health in all policies” – i.e. measures elsewhere than in the health sector (e.g. day-care, education, food industry, community planning). (12)

Benefits

Short-term benefits

N/A

Long-term benefits

- Early identification of individuals in need of more intensive medical follow-up or intervention (consensus)

- Potentially better cognitive development and peer relationships (consensus)
- Potentially reduced risk of cardiometabolic disease in later life (consensus)
- Potentially reduced risk of other non-communicable diseases (e.g. pulmonary disease) (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family as well as children and adults born preterm		
1. Parents and family as well as children and adults born preterm are informed by healthcare professionals about principles of healthy lifestyle, such as prevailing nutrition and physical activity recommendations, and about cardiometabolic risk factors and their follow-up in the healthcare system. (1–5)	A (High quality) B (High quality)	Patient information sheet
For healthcare professionals		
2. A guideline on detecting cardiometabolic risk factors is adhered to by all healthcare professionals (follow-up clinics, primary healthcare) encountering children and adults born preterm and appropriate advice and interventions are ensured, including national/European/International population guidelines. (13–16)	A (High quality) B (High quality)	Guideline
3. Blood pressure is measured every 2 years after 3 years of age for all children and those with high blood pressure are referred to specialist evaluation. (17)	A (Moderate quality) B (High quality)	Guideline
4. Physical activity, diet and other aspects of healthy lifestyle are assessed and adequate support to promote healthy lifestyle as necessary is provided. (13)	A (Moderate quality) B (High quality)	Guideline
5. Training on the assessment of cardiometabolic risk factors in preterm born children and adults and on healthy lifestyle is attended by all responsible healthcare professionals.	B (High quality)	Training documentation
For neonatal unit, hospital, and follow-up team		
6. A guideline on the assessment of cardiometabolic risk factors in children	B (High quality)	Guideline

and adults born preterm is available and regularly updated.		
7. Information on healthy lifestyle and cardiometabolic risk factors is included in discharge planning and follow-up visits and communicated to primary care providers. (1–5)	A (High quality) B (High quality)	Patient information sheet
8. Training on the assessment of cardiometabolic risk factors in preterm born children and adults and on healthy lifestyle is ensured.	B (High quality)	Training documentation
For health service		
9. A national guideline on the assessment of cardiometabolic risk factors including children and adults born preterm is available and regularly updated.	B (High quality)	Guideline
10. Benchmarking of neonatal units to include long-term measures of cardiometabolic health is ensured. (11,18)	B (Moderate quality)	Audit report

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, hospital and follow-up team	
N/A	
For health service	
Develop evidence-base for preventive strategies.	A (Low quality)

Getting started

Initial steps
For parents and family
Parents and family, as well as children and adults born preterm are informed by healthcare professionals about principles of healthy lifestyle, such as prevailing nutrition and physical activity recommendations.
For healthcare professionals
Incorporate healthy lifestyle counselling in the training of neonatal follow-up healthcare professionals.

- Attend training on the assessment of cardiometabolic risk factors in preterm born children and adults and on healthy lifestyle.

For neonatal unit, hospital, and follow-up team

- Develop written information material on cardiometabolic risk factors and healthy lifestyle for parents and children and adults born preterm.
- Develop and implement a guideline on the assessment of cardiometabolic risk factors in children and adults born preterm.
- Support healthcare professionals to participate in training on the assessment of cardiometabolic risk factors in preterm born children and adults and on healthy lifestyle.

For health service

- Develop and implement a national guideline on the assessment of cardiometabolic risk factors in children and adults, including those born preterm.

Source

1. Hovi P, Vohr B, Ment LR, Doyle LW, McGarvey L, Morrison KM, et al. Blood Pressure in Young Adults Born at Very Low Birth Weight: Adults Born Preterm International Collaboration. *Hypertens Dallas Tex* 1979. 2016;68(4):880–7.
2. de Jong F, Monuteaux MC, van Elburg RM, Gillman MW, Belfort MB. Systematic review and meta-analysis of preterm birth and later systolic blood pressure. *Hypertens Dallas Tex* 1979. 2012 Feb;59(2):226–34.
3. Parkinson JRC, Hyde MJ, Gale C, Santhakumaran S, Modi N. Preterm birth and the metabolic syndrome in adult life: a systematic review and meta-analysis. *Pediatrics*. 2013 Apr;131(4):e1240-1263.
4. Hovi P, Andersson S, Eriksson JG, Järvenpää A-L, Strang-Karlsson S, Mäkitie O, et al. Glucose Regulation in Young Adults with Very Low Birth Weight. *N Engl J Med*. 2007 May 17;356(20):2053–63.
5. Morrison KM, Ramsingh L, Gunn E, Streiner D, Lieshout RV, Boyle M, et al. Cardiometabolic Health in Adults Born Premature With Extremely Low Birth Weight. *Pediatrics*. 2016 Sep 2;e20160515.
6. Crane JD, Yellin SA, Ong FJ, Singh NP, Konyer N, Noseworthy MD, et al. ELBW survivors in early adulthood have higher hepatic, pancreatic and subcutaneous fat. *Sci Rep*. 2016 17;6:31560.
7. Kaseva N, Wehkalampi K, Strang-Karlsson S, Salonen M, Pesonen A-K, Räikkönen K, et al. Lower conditioning leisure-time physical activity in young adults born preterm at very low birth weight. *PloS One*. 2012;7(2):e32430.
8. Svedenkrans J, Henckel E, Kowalski J, Norman M, Bohlin K. Long-Term Impact of Preterm Birth on Exercise Capacity in Healthy Young Men: A National Population-Based Cohort Study. *PLOS ONE*. 2013 Dec 6;8(12):e80869.
9. Gibson A-M, Doyle LW. Respiratory outcomes for the tiniest or most immature infants. *Semin Fetal Neonatal Med*. 2014 Apr;19(2):105–11.
10. Hovi P, Andersson S, Järvenpää A-L, Eriksson JG, Strang-Karlsson S, Kajantie E, et al. Decreased bone mineral density in adults born with very low birth weight: a cohort study. *PLoS Med*. 2009 Aug;6(8):e1000135.
11. Raju TNK, Pemberton VL, Saigal S, Blaisdell CJ, Moxey-Mims M, Buist S, et al. Long-Term Healthcare Outcomes of Preterm Birth: An Executive Summary of a Conference Sponsored by the National Institutes of Health. *J Pediatr*. 2017 Feb;181:309-318.e1.
12. World Health Organization. Ottawa Charter for Health Promotion, 1986. 1986;



13. World Health Organization. Global recommendations on physical activity for health. [Internet]. 2010 [cited 2018 Jun 7]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK305057/>
14. World Health Organization. Healthy diet. Factsheet N°394 [Internet]. 2015. Available from: http://www.who.int/nutrition/publications/nutrientrequirements/healthydiet_factsheet394.pdf
15. Physical Activity Guidelines Advisory Committee. Physical Activity Guidelines Advisory Committee Report, 2008 [Internet]. Washington, DC: U.S. Department of Health and Human Services; 2008 [cited 2018 Jun 7]. Available from: <https://health.gov/paguidelines/report/pdf/CommitteeReport.pdf>
16. NHS Foundation Trust. Physical activity guidelines for children (under 5 years) [Internet]. <https://www.nhs.uk/live-well/exercise/physical-activity-guidelines-children-under-five-years/>. [cited 2018 Jun 22]. Available from: <https://www.nhs.uk/Livewell/fitness/Documents/children-under-5-years.pdf>
17. Lurbe E, Agabiti-Rosei E, Cruickshank JK, Dominiczak A, Erdine S, Hirth A, et al. 2016 European Society of Hypertension guidelines for the management of high blood pressure in children and adolescents. *J Hypertens*. 2016;34(10):1887–920.
18. Raju TNK, Buist AS, Blaisdell CJ, Moxey-Mims M, Saigal S. Adults born preterm: a review of general health and system-specific outcomes. *Acta Paediatr*. 106(9):1409–37.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Kajantie E, Leemhuis AG et al., European Standards of Care for Newborn Health: Healthy lifestyle and cardiovascular risk factors. 2018.

Hearing screening

Oudesluys-Murphy AM, Leemhuis AG, Wolke D, van Straaten HLM

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care) and parents

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Standardised hearing screening is conducted using Automated Auditory Brainstem Response (AABR) 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.

Rationale

The goal of this standard is to ensure screening and evaluation of hearing function in high-risk newborn infants and start auditory habilitation and follow-up for those infants with diagnosed congenital or early hearing impairment. (1–4)

Permanent childhood hearing impairment (PCHI) has a prevalence of 1 per 1000 live-born children, rising to 6 per 1000 at school age and is usually defined as hearing impairment of 30 dB or more in the better ear. (4–6) Even this relatively limited hearing loss will impair language and speech development with lasting consequences. (7,8) Social and emotional development and academic achievements will also be affected. (9–15)

When the hearing impaired child is identified shortly after birth and appropriate interventions are promptly started, with family counselling and amplification with hearing aids or cochlear implants for the child, the gains are enormous. (7,10) Studies have shown that this can enable a child who is deaf or severely hard of hearing to achieve better outcomes in language and speech development, very often within the normal range, with ultimately much improved social, academic, and work achievements in adult life. (6,7,9,10)

Monitoring and follow-up, especially in the pre-lingual period, is essential, for all children with hearing loss and especially those with risk factors for progressive or late onset hearing impairment. (16)

Benefits

Short-term benefits

N/A

Long-term benefits

- Early counselling to engage parents in their child's special needs (16,17)
- Early initiation of interventions (3,4,8)
- Improved use of various means of communication (e.g. visual, tactile, and other stimuli) with a hearing impaired child from the earliest possible age (3)
- Improved parent-child interaction and bonding (16,18)
- Prevented or reduced language and speech developmental problems (7)
- Prevented or reduced social and emotional problems (9)

- Improved chances for attending mainstream education with better academic achievements (6,10), as well as optimal study and training opportunities with prospects for better work and financial potentials (11)
- Reduced societal and educational costs (12–15)
- Increased quality of life of children, parents and families (19,20)
- Broader medical investigations which might not otherwise be initiated. Hearing impairment is often associated with other disorders and occurs frequently as part of a specific genetic syndrome (16)
- Provides feedback for perinatal and public health records (11)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed about universal neonatal hearing screening, and invited and encouraged by healthcare professionals to participate. (4,5)	A (High quality) B (High quality)	Patient information sheet
2. Parents receive standardised feedback about the results of their child's hearing screening in language that is accessible to them.	B (Moderate quality)	Parent feedback
3. Parents of children with a 'failed' hearing screening outcome are invited and encouraged by healthcare professionals to attend diagnostic assessments regarding cause, type and degree of hearing loss within three months of birth. (3–5)	A (High quality) B (High quality)	Clinical records, guideline, patient information sheet
4. Parents of children with permanent childhood hearing impairment (PCHI) are invited and encouraged by healthcare professionals to begin interventions including family guidance and amplification for the child as early as possible after diagnosis, certainly within six months of birth. (3–6)	A (High quality) B (High quality)	Guideline, patient information sheet
5. Parents have the opportunity to have contact with other parents of young children with hearing loss.	B (Moderate quality)	Patient information sheet
6. Parents are asked for permission to allow their child's medical and educational information to be used for outcome measures.	B (Low quality)	Parent consent, patient information sheet

- | | | |
|---|----------------------|----------------|
| 7. Parents are asked to consent to share the results of their child's hearing screening tests with education providers. | B (Moderate quality) | Parent consent |
|---|----------------------|----------------|

For healthcare professionals

- | | | |
|---|--------------------------------------|-------------------------|
| 8. A guideline on hearing screening of all newborn infants using an appropriate validated objective screening method within one month of birth, or term equivalent age as well as gold standard audiological diagnostic investigations to evaluate the type and degree of hearing impairment when the hearing screening is not "passed" by the screening method is adhered to by all healthcare professionals. (3,4,21) | A (High quality)
B (High quality) | Guideline |
| 9. The screening method used is appropriate to the child and situation, e.g. very preterm infants are screened using AABR because of the risk of post cochlear pathology. (3,4,21) | A (High quality) | Audit report, guideline |
| 10. Training on hearing screening and gold standard audiological diagnostic assessments used to evaluate the type and degree of hearing impairment when the hearing screening is not "passed", is attended by all responsible healthcare professionals (screeners). (3,4,21) | A (High quality)
B (High quality) | Training documentation |
| 11. A guideline on diagnostic evaluation and early interventions to be started as early as possible after the diagnosis of hearing impairment and certainly before the age of 6 months, as well as on appropriate and adequate follow-up of children with hearing loss (including late-onset types) is adhered to by all healthcare professionals. (3,4,16,21) | A (High quality)
B (High quality) | Guideline |

For neonatal unit, hospital and follow-up team

- | | | |
|---|--------------------------------------|--------------|
| 12. A guideline on hearing screening and referral for further interventions where necessary is available and regularly updated. | B (High quality) | Guideline |
| 13. Appropriate screening facilities and screeners are provided in hospitals where infants are born or admitted during the first weeks of life and also, when appropriate, in public health child services. (3,4) | A (High quality)
B (High quality) | Audit report |

14. Training on hearing screening and gold standard audiological diagnostic assessments used to evaluate the type and degree of hearing impairment when the hearing screening is not “passed”, is ensured.	B (High quality)	Training documentation
For health service		
15. A national guideline on universal neonatal hearing screening and referral for further interventions where necessary is available and regularly updated.	B (High quality)	Guideline
16. A national legal framework and funding is provided for hearing screening, diagnostic investigations, auditory habilitation, education, care, and follow-up. (3–5)	A (High quality) B (Moderate quality)	Legal framework

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
• Ensure that parents who are deaf or severely hard of hearing themselves are sufficiently supported by a case manager and speech-to sign language interpreters and all other necessary communication methods.	B (High quality)
• Provide funding to allow parents who are socially disadvantaged to participate in the follow-up hearing evaluations and interventions.	B (High quality)
For healthcare professionals	
• If required, provide sign interpreter.	B (Moderate quality)
For neonatal unit, hospital, and follow-up team	
N/A	
For health service	
• Evaluate and institute very early amplification (22)	A (High quality)

Getting started

Initial steps

For parents and family

- Parents are informed about the availability of neonatal hearing screening facilities and the importance of attending, and when necessary, also attending for diagnostic investigations after a ‘failed’ screen result.

For healthcare professionals

- Attend training on hearing screening and gold standard audiological diagnostic assessments used to evaluate the type and degree of hearing impairment when the hearing screening is not “passed”.
- Promote awareness of the devastating effects of congenital and early childhood hearing impairment and the significant benefits of early detection and habilitation of hearing impairment.
- Use any available tool to test hearing in a standard way for screening.

For neonatal unit, hospital, and follow-up team

- Develop and implement a guideline on neonatal hearing screening.
- Develop information material on neonatal hearing screening for parents.
- Provide a service to perform standardised hearing screening.
- Support healthcare professionals to participate in training on neonatal hearing screening.
- Provide a service to perform standardised hearing screening.

For health service

- Develop and implement a national guideline on universal neonatal hearing screening.
- Work towards having facilities in place for those who fail the screening with adequate and appropriate diagnostic and habilitation facilities available for all.

Source

1. Veen S, Sassen ML, Schreuder AM, Ens-Dokkum MH, Verloove-Vanhorick SP, Brand R, et al. Hearing loss in very preterm and very low birthweight infants at the age of 5 years in a nationwide cohort. *Int J Pediatr Otorhinolaryngol*. 1993 Feb;26(1):11–28.
2. Holsti A, Adamsson M, Serenius F, Häggglöf B, Farooqi A. Two-thirds of adolescents who received active perinatal care after extremely preterm birth had mild or no disabilities. *Acta Paediatr*. 2016 Nov 1;105(11):1288–97.
3. American Academy of Pediatrics, Joint Committee on Infant Hearing. Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*. 2007 Oct;120(4):898–921.
4. Joint Committee on Infant Hearing of the American Academy of Pediatrics, Muse C, Harrison J, Yoshinaga-Itano C, Grimes A, Brookhouser PE, et al. Supplement to the JCIH 2007 position statement: principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Pediatrics*. 2013 Apr;131(4):e1324-1349.
5. Nelson HD, Bougatsos C, Nygren P, 2001 US Preventive Services Task Force. Universal newborn hearing screening: systematic review to update the 2001 US Preventive Services Task Force Recommendation. *Pediatrics*. 2008 Jul;122(1):e266-276.
6. Korver AMH, Konings S, Dekker FW, Beers M, Wever CC, Frijns JHM, et al. Newborn hearing screening vs later hearing screening and developmental outcomes in children with permanent childhood hearing impairment. *JAMA*. 2010 Oct 20;304(15):1701–8.
7. Yoshinaga-Itano C, Sedey AL, Coulter DK, Mehl AL. Language of early- and later-identified children with hearing loss. *Pediatrics*. 1998 Nov;102(5):1161–71.
8. Moeller MP. Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics*. 2000 Sep;106(3):E43.
9. Netten AP, Rieffe C, Theunissen SCPM, Soede W, Dirks E, Korver AMH, et al. Early identification: Language skills and social functioning in deaf and hard of hearing preschool children. *Int J Pediatr Otorhinolaryngol*. 2015 Dec;79(12):2221–6.

10. Pimperton H, Blythe H, Kreppner J, Mahon M, Peacock JL, Stevenson J, et al. The impact of universal newborn hearing screening on long-term literacy outcomes: a prospective cohort study. *Arch Dis Child*. 2016 Jan;101(1):9–15.
11. Garramiola-Bilbao I, Rodríguez-Álvarez A. Linking hearing impairment, employment and education. *Public Health*. 2016 Dec 1;141:130–5.
12. Bubbico L, Bartolucci MA, Broglio D, Boner A. [Societal cost of pre-lingual deafness]. *Ann Ig Med Prev E Comunita*. 2007 Apr;19(2):143–52.
13. Francis HW, Koch ME, Wyatt JR, Niparko JK. Trends in educational placement and cost-benefit considerations in children with cochlear implants. *Arch Otolaryngol Head Neck Surg*. 1999 May;125(5):499–505.
14. Mohr PE, Feldman JJ, Dunbar JL, McConkey-Robbins A, Niparko JK, Rittenhouse RK, et al. The societal costs of severe to profound hearing loss in the United States. *Int J Technol Assess Health Care*. 2000;16(4):1120–35.
15. Schroeder L, Petrou S, Kennedy C, McCann D, Law C, Watkin PM, et al. The economic costs of congenital bilateral permanent childhood hearing impairment. *Pediatrics*. 2006 Apr;117(4):1101–12.
16. Korver AMH, Smith RJH, Van Camp G, Schleiss MR, Bitner-Glindzicz MAK, Lustig LR, et al. Congenital hearing loss. *Nat Rev Dis Primer*. 2017 12;3:16094.
17. Decker KB, Vallotton CD, Johnson HA. Parents' communication decision for children with hearing loss: sources of information and influence. *Am Ann Deaf*. 2012;157(4):326–39.
18. Weisel A, Kamara A. Attachment and individuation of deaf/hard-of-hearing and hearing young adults. *J Deaf Stud Deaf Educ*. 2005;10(1):51–62.
19. Duarte I, Santos CC, Rego G, Nunes R. Health-related quality of life in children and adolescents with cochlear implants: self and proxy reports. *Acta Otolaryngol (Stockh)*. 2014 Sep;134(9):881–9.
20. Vaccari C, Marschark M. Communication between parents and deaf children: implications for social-emotional development. *J Child Psychol Psychiatry*. 1997 Oct;38(7):793–801.
21. Ching TYC, Dillon H, Button L, Seeto M, Van Buynder P, Marnane V, et al. Age at Intervention for Permanent Hearing Loss and 5-Year Language Outcomes. *Pediatrics*. 2017 Sep;140(3).
22. Lam MYY, Wong ECM, Law CW, Lee HHL, McPherson B. Maternal knowledge and attitudes to universal newborn hearing screening: Reviewing an established program. *Int J Pediatr Otorhinolaryngol*. 2018 Feb;105:146–53.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Oudesluys-Murphy AM, Leemhuis AG et al., European Standards of Care for Newborn Health: Hearing screening. 2018.



Immunisation of preterm infants

Härtel C, Wolke D, Leemhuis AG, Mader S, Fortmann I, Göttler D, Hüning B, Liese J

Target group

Infants born very preterm and those preterm infants with risk factors (see preamble of Follow-up & continuing care), parents, and families

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Preterm infants are immunised according to their chronological age, regardless of gestational age and weight at birth. In very preterm infants, immunisations are started and monitored in hospital, once the target age for the first immunisation (usually 8-12 weeks) is reached.

Rationale

Preterm infants have a high vulnerability for infections due to the immaturity of the immune system including skin and mucosa barriers and reduced amounts of protective antibodies transferred through the placenta. This susceptibility is of particular importance for vaccine-preventable diseases such as pertussis, pneumococcal, H. influenzae type B, influenza and rotavirus infections. Severe disease courses of Rotavirus infections (including sepsis-like cases) have been noted for preterm infants. The vulnerable lung of preterm infants renders them susceptible for infections with respiratory syncytial virus (RSV), which often require hospitalisation and respiratory support. Preterm infants are at higher risk for long-term morbidities associated with complicated courses of infections, e.g. chronic lung disease. (1–3)

There are historical scepticism and uncertainties of healthcare professionals and parents about the immunogenicity and safety of vaccines administered to preterm infants. (4,5) While no apparent justifications for delaying vaccine administration exist, preterm infants are often not vaccinated according to national standards. (6,7) Studies, however, demonstrate that the preterm infant's immune system is competent to generate protective immune responses to vaccines which are similar to that obtained in term infants. (4,8) Schedule-based vaccination of preterm infants is known to prompt accelerated priming of protective immune components and therefore adds a benefit for vulnerable infants by reducing the risk for infectious and respiratory morbidity during childhood. (4–6,8–11) Combination vaccines such as hexavalent vaccines (diphtheria, pertussis, tetanus, polio, haemophilus type B and hepatitis B), pneumococcal vaccines and live vaccines such as rotavirus are suitable for preterm infants, well tolerated, safe and immunogenic. (9)

Infants <28 weeks of gestation or <32 weeks of gestation (as per national guideline) have a higher risk to respond to vaccination with apnoea, desaturations with SaO₂ <80% and bradycardia within 24 hours. Adequate monitoring in a hospital setting is justified as apnoea and desaturations with SaO₂ <80% for longer than 60 seconds increase the risk for adverse neurodevelopmental outcome. If the first vaccination is well tolerated (without apnoea/bradycardia) and the patient is discharged from hospital, subsequent immunisations can be performed in an outpatient setting. (2,12,13)

Epidemiological variations for vaccine-preventable diseases in Europe (e.g. tuberculosis, meningococcus B and meningococcus C infections) need consideration

for country-specific vaccination schedules of preterm infants. A few countries mostly in Eastern Europe recommend immunisation with *Bacillus Calmette-Guerin* against tuberculosis as soon as possible after birth for late to moderate preterm infants >31 weeks of gestation.

Non-specific hygienic measures are important. Preterm and term infants benefit from non-specific preventive measures against infections including breastfeeding, up-to-date immunisation schedule of family members and avoiding the exposure to tobacco smoke, contact with ill individuals and crowds. (3)

Equal access to timely vaccinations for preterm and term infants across the EU should be promoted.

Benefits

Short-term benefits

- Improved awareness among parents and healthcare professionals for vaccine-preventable diseases and the immunological competence of preterm infants (consensus)
- Increased information of parents about immunisations during hospital stay to avoid missed opportunities (see Transition from hospital to home) (7)
- Increased vaccine coverage in this risk group which leads to reduced general burden of infectious diseases (2)
- Intensified safety monitoring and avoidance of unnecessary sepsis evaluations in the post-vaccination period (7)

Long-term benefits

- Alleviated parent and provider vaccine safety concerns and improved confidence in vaccinating high-risk infants after hospital discharge (consensus)
- Increased rate of complete, schedule-based immunisation in preterm infants (7)
- Reduced healthcare costs and costs for the family (i.e. hospital readmissions) (consensus)
- Reduced risk of transmitting vaccine-preventable infectious diseases in childcare and school settings (consensus)
- Increased sensitivity for preterm birth related complications including problems of parent-infant interaction due to schedule-based immunisation appointments (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals about immunisations given during hospitalisation. (14)	A (High quality) B (High quality)	Parent feedback, patient information sheet
2. Parents are informed by healthcare professionals about immunisations given at discharge from neonatal care. Also including information on the importance of completion of	A (High quality) B (High quality)	Parent feedback, patient information sheet

immunisation according to the immunisation schedule and avoiding delays so infants are reliably protected when attending early day care. (14)

- | | | |
|--|--------------------------------------|--|
| 3. Family members, household and other close contacts of the preterm infant are immunised according to national recommendations, considering the risk of transmission of vaccine-preventable diseases, e.g. pertussis or influenza (preventive concept of “cocooning”). (15) | A (High quality) | Parent feedback, patient information sheet |
| 4. Discharge planning includes information about non-specific hygienic measures and avoidance of unnecessary exposures, and an individualised immunisation schedule adapted to the infants’ medical conditions and risk factors. (14–17) | A (High quality)
B (High quality) | Parent feedback, patient information sheet |

For healthcare professionals

- | | | |
|---|--------------------------------------|--|
| 5. A unit guideline on immunisation during and after hospitalisation (neonatal care/follow-up care) is adhered to by all healthcare professionals, e.g. verification of immunisation status at every follow-up visit. | B (High quality) | Guideline, training documentation, clinical record |
| 6. Training on current national immunisation guidelines, including safety and efficacy data of vaccines related to preterm infants, is attended by all responsible healthcare professionals. Training of communication skills as of provider vaccine communication in paediatric populations is critical to alleviate scepticism. | B (High quality) | Guideline, training documentation |
| 7. Immunisation is initiated according to the chronological age of preterm babies, regardless of gestational age and weight at birth. In very preterm infants, immunisations are started in hospital, once the target age of 8-12 weeks for the first immunisation is reached. (3,4,6,18) | A (High quality)
B (High quality) | Guideline |
| 8. Primary immunisation includes vaccination against Diphtheria, Pertussis, Tetanus, Polio, Haemophilus type B and Hepatitis B according to national immunisation schedule. This is | A (High quality)
B (High quality) | Guideline |

initiated in early infancy (e.g. at 2, 3, 4 months of age) followed by a booster immunisation e.g. at 11-24 months of age. (3,4,11)

- | | | |
|---|--------------------------------------|---|
| 9. Immunisation against <i>Streptococcus pneumoniae</i> (pneumococci) and <i>Neisseria meningitidis</i> (meningococci) is initiated as per national or unit guideline. Rotavirus vaccination can be given at age 6 weeks if ward infrastructure allows prevention of nosocomial transmission (immunised individuals may shed the virus, single room). Otherwise, rotavirus vaccination can be administered at discharge from neonatal care. Infants with signs or family history of immunodeficiency should not be vaccinated with live vaccines (BCG, rotavirus). (2,3,8–10) | A (High quality)
B (High quality) | Guideline |
| 10. Passive immune-prophylaxis against RSV are considered before hospital discharge of extremely preterm infants with additional risk factors during season. At six months of chronological age, preterm infants should be evaluated if they qualify for influenza immunisation, e.g. infants with chronic lung or heart disease. | B (High quality) | Guideline |
| 11. Training on application of vaccines in preterm infants, including injection and pain management procedures is attended by all responsible healthcare professionals. | B (High quality) | Guideline,
training
documentation |
| 12. Training on necessary safety monitoring precautions during and after immunisation during hospitalisation is attended by all responsible healthcare professionals. (2,12,13,19) | A (High quality)
B (High quality) | Guideline,
training
documentation |
| 13. Healthcare professionals document all provided immunisations in a standardised WHO standard compatible immunisation card. | B (High quality) | Guideline,
training
documentation |
| 14. A written proposal for an individualised immunisation schedule (included in the discharge summary) is communicated with the primary care physician and provided by healthcare professionals at the hospital. | B (Moderate quality) | Clinical records |

For neonatal unit, hospital, and follow-up team		
15. A unit guideline on immunisation during and after hospitalisation (neonatal care) is available and regularly updated.	B (High quality)	Guideline
16. Training on current national immunisation guidelines, including safety and efficacy data of vaccines related to preterm infants is ensured.	B (High quality)	Guideline, training documentation
17. For immunisations during neonatal care preterm infants are clinically stable and not expecting surgery within the next 3 days for inactivated vaccines and 14 days for live virus vaccines.	B (High quality)	Guideline, clinical records
18. First immunisation of preterm infants <28 weeks of age in hospital is ensured, i.e. during primary stay or readmission, and monitored for 24-72 hours post immunisation as per local guideline in order to detect apnoea and/or bradycardia events. In addition, critical indication of sepsis evaluations post-vaccination is ensured.	B (High quality)	Guideline, clinical records
For health service		
19. A national guideline on recommended preterm immunisations is available and regularly updated.	B (High 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 N/A	
For hospital	
Conduct more research on yet neglected aspects of immunisation practice in preterm infants (e.g. role of breast-milk feeding, probiotics, microbiome on vaccine responses)	B (Moderate quality)
For health service	
Provide financial resources for research on yet neglected aspects of immunisation practice in preterm infants	B (Moderate quality)

Getting started

Initial steps

For parents and family

- Parents and family receive flyer and information sheets about specific preterm oriented prevention of infectious diseases by active and passive immunisation strategies.

For healthcare professionals

- Attend training on the assessment of discharge readiness using current national immunisation guidelines, including safety and efficacy data of vaccines related to preterm infants.
- Establish a structure of communication with primary care physician, community/healthcare services and follow-up services regarding the timing of immunisations.

For neonatal unit, hospital, and follow-up team

- Develop and implement a unit guideline for the assessment of the preterm child's immunisation status at the time of discharge from hospital and at every follow-up visit (e.g. 3, 6 and 12 months).
- Develop and implement a unit guideline on the immunisations to be recommended after discharge from hospital to home.
- Develop information material on different vaccine-preventable infectious diseases and the related vaccines for parents.
- Support healthcare professionals to participate in training on the assessment of discharge readiness using current national immunisation guidelines, including safety and efficacy data of vaccines related to preterm infants.

For health service

- Develop and implement a national guideline on immunisation in preterm infants.
- Enable easy access for parents to vaccination through paediatricians in outpatient care.
- Define quality markers for discharge care.

Description

Core elements of immunisations in preterm infants are:

- **Infant:** completion of immunisations according to infants age and underlying chronic conditions
- **Family:** check immunisation status of family members and household contacts including influenza, pneumococcal and pertussis boosters of family members (cocooning strategy). Inform parents/mothers of vaccines recommended during pregnancy (Influenza, pertussis) for protection of infants via active antibody transfer to newborn infants, especially during the third trimester. Consider pertussis booster immunisations in adolescence and adulthood to increase immunity against pertussis and prevent transmission to newborn infants. Seasonal influenza immunisation of pregnant women is associated with reduced risk for preterm birth and respiratory morbidity in the offspring.
- **Community/healthcare system:** development of a comprehensive individualised immunisation schedule for further completing immunisation series started in the hospital during preterm care. Make appointments for further booster immunisations, which require post immunisation cardio-respiratory monitoring.

Example of a checklist used to address immunisation during discharge management

1. Discharge readiness

a. INFANT

- Immunisation status adequate according to chronological age and underlying conditions?
- Infant qualifies for specific vaccines at discharge, as influenza, or Rotavirus vaccine or passive immunisation against RSV

b. PARENTS

- Counsel about necessary immunisations according to infants chronological age and underlying conditions.
- Inform parents about update of the immunisation status in all family and household or other close contacts (e.g. grandparents).

c. COMMUNITY/HEALTHCARE SYSTEM

- Primary care and medical special care physicians informed about infant's immunisation status and further necessary booster and primary vaccine doses (individualised immunisation plan).
- If necessary, provide information to primary care and medical special care physicians about previous vaccine responses/side effects and if necessary safety monitoring in further vaccine doses.
- Appointments for follow-up immunisations documented in discharge letter, are arranged and confirmed with parents and primary care physician.

2. Pre-discharge screening and care procedures

- Start full immunisation following chronologic age, consider RSV prophylaxis and influenza immunisation, if applicable.

3. Parental competencies

- Strengthen knowledge about immunisation importance, appointments and documentation.

Source

1. Humberg A, Fortmann I, Siller B, Kopp MV, Herting E, Göpel W, et al. Preterm birth and sustained inflammation: consequences for the neonate. *Semin Immunopathol.* 2020 Aug;42(4):451–68.
2. Bonhoeffer J, Siegrist CA, Heath PT. Immunisation of premature infants. *Archives of Disease in Childhood.* 2006 Nov 1;91(11):929–35.
3. Doherty M, Schmidt-Ott R, Santos JI, Stanberry LR, Hofstetter AM, Rosenthal SL, et al. Vaccination of special populations: Protecting the vulnerable. *Vaccine.* 2016 20;34(52):6681–90.
4. Faldella G, Galletti S, Corvaglia L, Ancora G, Alessandroni R. Safety of DTaP–IPV–Hib–HBV hexavalent vaccine in very premature infants. *Vaccine.* 2007 Jan 22;25(6):1036–42.
5. Salmon DA, Dudley MZ, Glanz JM, Omer SB. Vaccine Hesitancy: Causes, Consequences, and a Call to Action. *Am J Prev Med.* 2015 Dec;49(6 Suppl 4):S391–398.

6. Stichtenoth G, Härtel C, Spiegler J, Dördelmann M, Möller J, Wieg C, et al. Increased risk for bronchitis after discharge in non-vaccinated very low birth weight infants. *Klin Padiatr.* 2015 Mar;227(2):80–3.
7. Hofstetter AM, Jacobson EN, deHart MP, Englund JA. Early Childhood Vaccination Status of Preterm Infants. *Pediatrics.* 2019 Sep 1;144(3):e20183520.
8. Shinefield H, Black S, Ray P, Fireman B, Schwalbe J, Lewis E. Efficacy, immunogenicity and safety of heptavalent pneumococcal conjugate vaccine in low birth weight and preterm infants. *Pediatr Infect Dis J.* 2002 Mar;21(3):182–6.
9. Omenaca F, Sarlangue J, Szenborn L, Nogueira M, Suryakiran PV, Smolenov IV, et al. Safety, Reactogenicity and Immunogenicity of the Human Rotavirus Vaccine in Preterm European Infants: A Randomized Phase IIIb Study. *The Pediatric Infectious Disease Journal.* 2012 May;31(5):487–93.
10. Duan K, Guo J, Lei P. Safety and Immunogenicity of Pneumococcal Conjugate Vaccine in Preterm Infants: A Meta-Analysis. *Indian J Pediatr.* 2017 Feb;84(2):101–10.
11. Blondheim O, Bader D, Abend M, Peniakov M, Reich D, Potesman I, et al. Immunogenicity of hepatitis B vaccine in preterm infants. *Archives of Disease in Childhood - Fetal and Neonatal Edition.* 1998 Nov 1;79(3):F206–8.
12. Flatz-Jequier A, Posfay-Barbe KM, Pfister RE, Siegrist CA. Recurrence of cardiorespiratory events following repeat DTaP-based combined immunization in very low birth weight premature infants. *J Pediatr.* 2008 Sep;153(3):429–31.
13. Aaby P, Benn CS, Flanagan KL, Klein SL, Kollmann TR, Lynn DJ, et al. The non-specific and sex-differential effects of vaccines. *Nat Rev Immunol.* 2020 Aug;20(8):464–70.
14. Tozzi AE, Piga S, Corchia C, Di Lallo D, Carnielli V, Chiandotto V, et al. Timeliness of routine immunization in a population-based Italian cohort of very preterm infants: results of the ACTION follow-up project. *Vaccine.* 2014 Feb 7;32(7):793–9.
15. Maertens K, Orije MRP, Van Damme P, Leuridan E. Vaccination during pregnancy: current and possible future recommendations. *Eur J Pediatr.* 2020 Feb;179(2):235–42.
16. Di Mauro A, Di Mauro F, Greco C, Giannico OV, Grosso FM, Baldassarre ME, et al. In-hospital and web-based intervention to counteract vaccine hesitancy in very preterm infants' families: a NICU experience. *Italian Journal of Pediatrics.* 2021 Sep 16;47(1):190.
17. Kollmann TR, Marchant A, Way SS. Vaccination strategies to enhance immunity in neonates. *Science.* 2020 May 8;368(6491):612–5.
18. Fortmann I, Dammann MT, Humberg A, Siller B, Stichtenoth G, Engels G, et al. Five Year Follow Up of Extremely Low Gestational Age Infants after Timely or Delayed Administration of Routine Vaccinations. *Vaccines (Basel).* 2021 May 12;9(5):493.
19. Lee J, Robinson JL, Spady DW. Frequency of apnea, bradycardia, and desaturations following first diphtheria-tetanus-pertussis-inactivated polio-Haemophilus influenzae type B immunization in hospitalized preterm infants. *BMC Pediatr.* 2006 Jun 19;6:20.

First edition, September 2022

Lifecycle:

3 years/next revision: 2025

Recommended citation

EFCNI, Härtel C, Wolke D et al., European Standards of Care for Newborn Health: Immunisation of preterm infants. 2022.



Meeting special needs at school

Jaekel J, Johnson S, Wolke D, Leemhuis AG

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care) and parents

User group

Healthcare professionals, education professionals, neonatal units, hospitals, follow-up teams, and health services.

Statement of standard

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.

Rationale

The goals are to (i) evaluate school readiness prior to initial entry into formal schooling to inform educational provision and support, and (ii) provide information and training to education professionals in order to increase their awareness and knowledge of how to support the learning of children with developmental problems and disorders associated with perinatal risk.

Very preterm children or those with additional neonatal risk factors have an increased risk for poor academic attainment, learning difficulties, and special educational needs. (1–6) Neuropsychological sequelae include poor attentional (7,8) and inhibitory control (9), slower processing speed (10), problems with fine motor skills and visual-motor integration (11), deficits in executive function and working memory (12,13), general cognitive impairments (14,15), language problems (16), and difficulties with sensory processing (17). These cognitive abilities are important prerequisites for learning. (18) Deficits in these areas may limit children's abilities to profit from formal instruction in all school subjects, and particularly in mathematics. (2,19–22) Children's social and emotional difficulties (23,24) may also impact their attainment at school (see Follow-up & continuing care).

While parents and teachers often expect developmental catch-up with peers, studies show that the cognitive and academic difficulties of very preterm children persist throughout adolescence and adulthood. (25–29) In particular, teachers lack knowledge and formal training about preterm children's educational needs and how to facilitate their learning. (30) Thus, teachers need to be informed about the specific constellation of problems experienced by very preterm children. Early identification and individually tailored support may help children achieve their full academic potential. (31)

Benefits

Short-term benefits

N/A

Long-term benefits

- Early identification of children at risk for learning difficulties (1,32–34)

- Timely development of an individualised education plan and initiation of intervention for children with developmental problems or poor school readiness (consensus)
- Informed decisions about educational provision (consensus)
- Increased provision of training for education professionals (about the special educational needs of some very preterm children) (consensus)
- Potentially improved educational outcomes and life chances (consensus)
- Improved quality of life for preterm children and their families (consensus)
- Informed parental counselling and participation in educational decision making (consensus)
- Improved communication between parents, teachers, and healthcare professionals (with parental consent) (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and families		
1. Parents are informed by healthcare professionals about long-term developmental and educational outcomes of children born very preterm and invited to attend a follow-up programme, which includes screening for school readiness, 6-12 months prior to primary school entry, as well as screening for attention, cognitive, motor, and social-emotional problems, and deficits in early academic skills. (1,25–28,33–36)	A (High quality) B (High quality)	Patient information sheet
2. Parents receive standardised feedback about the results of their child's assessment in a language that is accessible to them, and they are informed about relevant educational policies (e.g. regarding school starting age). (37)	B (Moderate quality)	Parent feedback, patient information sheet
3. Parents of children identified at risk for developmental problems or poor school readiness are offered support prior to school entry, and throughout schooling. (31)	A (Moderate quality) B (Moderate quality)	Guideline, parent feedback
4. Parents are asked for consent to share the results of their child's screening and/or developmental tests with their school upon entry. (38)	B (High quality) C (High quality)	Parent consent

For education/healthcare professionals		
5. A guideline on screening for developmental problems and poor school readiness, (e.g. attention, cognitive, social-emotional, early academic skills, and sensory processing) carried out 6-12 months prior to school entry is adhered to by all responsible professionals. (8–10,13,15,38)	A (High quality) B (High quality)	Guideline
6. Training on standardised screening for developmental problems and poor school readiness is attended by all responsible professionals.	B (High quality)	Training documentation
For neonatal unit, hospital, and follow-up team		
7. A unit guideline on screening for developmental problems and school readiness is available and regularly updated.	B (High quality)	Guideline
8. Training on standardised screening for developmental problems and poor school readiness is ensured.	B (High quality)	Training documentation
For health and education services		
9. A national guideline on screening for developmental problems and school readiness is available and regularly updated.	B (High quality)	Guideline
10. Pathways and a legal framework are established for obtaining parental consent and sharing of information between health and education services.	C (High quality)	Information sharing protocol and legal guidelines

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
• Provide funding for disadvantaged families to participate in screening services. (39–41)	A (High quality)
• Provide resources to encourage parents to participate in their child's educational support planning. (39–41)	A (High quality)
For education/healthcare professionals	
• Develop teaching methods and strategies that help provide tailored support for very preterm children in the classroom. (30)	A (High quality)
For neonatal unit, hospital, and follow-up team	
N/A	

For health services

- Establish system for data sharing between education and health providers. B (High quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about the importance of developmental screening and assessment, and the sharing of information with schools and education professionals.

For education/healthcare professionals

- Define what school readiness entails according to national or regional policies and identify age-appropriate screening tools or formal tests.
- Attend training on standardised screening for developmental problems and poor school readiness (professionals providing follow-up and screening services).
- Attend training on providing feedback and advice on educational needs.

For neonatal unit, hospital, and follow-up team

- Develop and implement a guideline on screening for developmental problems and school readiness.
- Develop information on follow-up including developmental screening and assessment of school readiness for parents.
- Establish a clinical pathway from discharge to screening at 6-12 months prior to school entry.

For health service

- Develop and implement a national guideline on screening for developmental problems and school readiness.
- Initiate data linkage between health and education service providers.
- Explore legal guidelines and parental consent framework.

Source

1. MacKay DF, Smith GCS, Dobbie R, Pell JP. Gestational Age at Delivery and Special Educational Need: Retrospective Cohort Study of 407,503 Schoolchildren. Lau TK, editor. PLoS Med. 2010 Jun 8;7(6):e1000289.
2. Johnson S, Hennessy E, Smith R, Trikic R, Wolke D, Marlow N. Academic attainment and special educational needs in extremely preterm children at 11 years of age: the EPICure study. Arch Dis Child - Fetal Neonatal Ed. 2009 Jul 1;94(4):F283–9.
3. Clark CAC, Fang H, Espy KA, Filipek PA, Juranek J, Bangert B, et al. Relation of neural structure to persistently low academic achievement: a longitudinal study of children with differing birth weights. Neuropsychology. 2013 May;27(3):364–77.
4. Espy KA, Fang H, Charak D, Minich N, Taylor HG. Growth mixture modeling of academic achievement in children of varying birth weight risk. Neuropsychology. 2009 Jul;23(4):460–74.
5. Schermann L, Sedin G. Cognitive function at 10 years of age in children who have required neonatal intensive care. Acta Paediatr Oslo Nor 1992. 2004 Dec;93(12):1619–29.
6. Luu TM, Ment LR, Schneider KC, Katz KH, Allan WC, Vohr BR. Lasting effects of preterm birth and neonatal brain hemorrhage at 12 years of age. Pediatrics. 2009 Mar;123(3):1037–44.



7. Bora S, Pritchard VE, Chen Z, Inder TE, Woodward LJ. Neonatal cerebral morphometry and later risk of persistent inattention/hyperactivity in children born very preterm. *J Child Psychol Psychiatry*. 2014 Jul;55(7):828–38.
8. Anderson PJ, De Luca CR, Hutchinson E, Spencer-Smith MM, Roberts G, Doyle LW, et al. Attention problems in a representative sample of extremely preterm/extremely low birth weight children. *Dev Neuropsychol*. 2011;36(1):57–73.
9. Jaekel J, Eryigit-Madzwamuse S, Wolke D. Preterm Toddlers' Inhibitory Control Abilities Predict Attention Regulation and Academic Achievement at Age 8 Years. *J Pediatr*. 2016 Feb;169:87–92.e1.
10. Mulder H, Pitchford NJ, Marlow N. Processing speed and working memory underlie academic attainment in very preterm children. *Arch Dis Child Fetal Neonatal Ed*. 2010 Jul;95(4):F267–272.
11. Geldof CJA, van Wassenae AG, de Kieviet JF, Kok JH, Oosterlaan J. Visual perception and visual-motor integration in very preterm and/or very low birth weight children: a meta-analysis. *Res Dev Disabil*. 2012 Apr;33(2):726–36.
12. Aarnoudse-Moens CSH, Smidts DP, Oosterlaan J, Duivenvoorden HJ, Weisglas-Kuperus N. Executive function in very preterm children at early school age. *J Abnorm Child Psychol*. 2009 Oct;37(7):981–93.
13. Anderson PJ, Doyle LW, Victorian Infant Collaborative Study Group. Executive functioning in school-aged children who were born very preterm or with extremely low birth weight in the 1990s. *Pediatrics*. 2004 Jul;114(1):50–7.
14. Rose SA, Feldman JF, Jankowski JJ, Van Rossem R. Basic Information Processing Abilities at 11 years Account for Deficits in IQ Associated with Preterm Birth. *Intelligence*. 2011 Jul;39(4):198–209.
15. Wolke D, Strauss VY-C, Johnson S, Gilmore C, Marlow N, Jaekel J. Universal gestational age effects on cognitive and basic mathematic processing: 2 cohorts in 2 countries. *J Pediatr*. 2015 Jun;166(6):1410-1416-2.
16. van Noort-van der Spek IL, Franken M-CJP, Weisglas-Kuperus N. Language functions in preterm-born children: a systematic review and meta-analysis. *Pediatrics*. 2012 Apr;129(4):745–54.
17. Geldof CJ, Oosterlaan J, Vuijk PJ, de Vries MJ, Kok JH, van Wassenae-Leemhuis AG. Visual sensory and perceptive functioning in 5-year-old very preterm/very-low-birthweight children. *Dev Med Child Neurol*. 2014 Sep;56(9):862–8.
18. Jaekel J, Baumann N, Wolke D. Effects of Gestational Age at Birth on Cognitive Performance: A Function of Cognitive Workload Demands. *PLOS ONE*. 2013 May 24;8(5):e65219.
19. Johnson S, Wolke D, Hennessy E, Marlow N. Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment. *Dev Neuropsychol*. 2011;36(1):74–95.
20. Simms V, Cragg L, Gilmore C, Marlow N, Johnson S. Mathematics difficulties in children born very preterm: current research and future directions. *Arch Dis Child Fetal Neonatal Ed*. 2013 Sep;98(5):F457-463.
21. Simms V, Gilmore C, Cragg L, Clayton S, Marlow N, Johnson S. Nature and origins of mathematics difficulties in very preterm children: a different etiology than developmental dyscalculia. *Pediatr Res*. 2015 Feb;77(2):389–95.
22. Jaekel J, Wolke D. Preterm birth and dyscalculia. *J Pediatr*. 2014 Jun;164(6):1327–32.
23. Ritchie K, Bora S, Woodward LJ. Social development of children born very preterm: a systematic review. *Dev Med Child Neurol*. 2015 Oct;57(10):899–918.
24. Heuser KM, Jaekel J, Wolke D. Origins and Predictors of Friendships in 6- to 8-Year-Old Children Born at Neonatal Risk. *J Pediatr*. 2018 Feb;193:93–101.e5.



25. Breeman LD, Jaekel J, Baumann N, Bartmann P, Wolke D. Attention problems in very preterm children from childhood to adulthood: the Bavarian Longitudinal Study. *J Child Psychol Psychiatry*. 2016 Feb;57(2):132–40.
26. Breeman LD, Jaekel J, Baumann N, Bartmann P, Wolke D. Preterm Cognitive Function Into Adulthood. *Pediatrics*. 2015 Sep;136(3):415–23.
27. Litt JS, Gerry Taylor H, Margevicius S, Schluchter M, Andreias L, Hack M. Academic achievement of adolescents born with extremely low birth weight. *Acta Paediatr Oslo Nor* 1992. 2012 Dec;101(12):1240–5.
28. Basten M, Jaekel J, Johnson S, Gilmore C, Wolke D. Preterm birth and adult wealth mathematics skills count. *Psychol Sci*. 2015;956797615596230.
29. Linsell L, Johnson S, Wolke D, O'Reilly H, Morris JK, Kurinczuk JJ, et al. Cognitive trajectories from infancy to early adulthood following birth before 26 weeks of gestation: a prospective, population-based cohort study. *Arch Dis Child*. 2018 Apr;103(4):363–70.
30. Johnson S, Gilmore C, Gallimore I, Jaekel J, Wolke D. The long-term consequences of preterm birth: what do teachers know? *Dev Med Child Neurol*. 2015 Jun;57(6):571–7.
31. van Veen S, Aarnoudse-Moens CSH, Oosterlaan J, van Sonderen L, de Haan TR, van Kaam AH, et al. Very preterm born children at early school age: Healthcare therapies and educational provisions. *Early Hum Dev*. 2018 Feb;117:39–43.
32. Doyle LW, Anderson PJ, Battin M, Bowen JR, Brown N, Callanan C, et al. Long term follow up of high risk children: who, why and how? *BMC Pediatr*. 2014 Nov 17;14:279.
33. Quigley MA, Poulsen G, Boyle E, Wolke D, Field D, Alfievic Z, et al. Early term and late preterm birth are associated with poorer school performance at age 5 years: a cohort study. *Arch Dis Child Fetal Neonatal Ed*. 2012 May;97(3):F167–173.
34. Lipkind HS, Slopen ME, Pfeiffer MR, McVeigh KH. School-age outcomes of late preterm infants in New York City. *Am J Obstet Gynecol*. 2012 Mar;206(3):222.e1–6.
35. Reimann M, Hüning B. Frühchen-App entlastet Eltern und Pflegende. *Pflegezeitschrift*. 2017 May 1;70(5):27–9.
36. Hüning BM, Reimann M, Beerenberg U, Stein A, Schmidt A, Felderhoff-Müser U. Establishment of a family-centred care programme with follow-up home visits: implications for clinical care and economic characteristics. *Klin Pädiatr*. 2012 Nov;224(7):431–6.
37. Jaekel J, Strauss VY-C, Johnson S, Gilmore C, Wolke D. Delayed school entry and academic performance: a natural experiment. *Dev Med Child Neurol*. 57(7):652–9.
38. REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).
39. Eryigit Madzwamuse S, Baumann N, Jaekel J, Bartmann P, Wolke D. Neuro-cognitive performance of very preterm or very low birth weight adults at 26 years. *J Child Psychol Psychiatry*. 2015 Aug;56(8):857–64.
40. Kißgen R, Carlitscheck J, Rapp C, Franke S. [Psychosocial care in institutional neonatology in Germany: a quantitative-empirical inventory from the medical professionals' perspective]. *Z Geburtshilfe Neonatol*. 2012 Dec;216(6):259–68.
41. Kane J, Riddell S, Banks P, Baynes A, Dyson A, Millward A, et al. Special educational needs and individualised education programmes: issues of parent and pupil participation. *Scott Educ Rev*. 2003;(35):38–48.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Jaekel J, Johnson S et al., European Standards of Care for Newborn Health: Meeting special needs at school. 2018.



Mental health

Johnson S, Jaekel J, Wolke D, Leemhuis AG

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care) and parents

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Behaviour, emotional and attention problems are assessed at two years of age and again at the time of transition to school.

Rationale

The goal is to assess and evaluate children's mental health, to identify those who would benefit from additional support, and to provide feedback to families and health services.

Infants born very preterm are at increased risk for mental health problems throughout childhood and adolescence, in particular for emotional and attention problems, the risk for which increases with lower gestational age at birth. (1,2) Up to 46% have clinically significant problems, (1) the pattern of which is consistent across cohorts and despite advances in neonatal care. (3,4) There is a two- to three-fold increased risk for psychiatric disorders (5) which is typically found to be specific to Attention Deficit/Hyperactivity Disorders (ADHD), particularly of the inattentive subtype, anxiety disorders and autism spectrum disorders. (6,7) Mental health problems are also evident during the pre-school years (6,8–11) and parent reports of problems at two to three years of age are associated with disorders later in childhood. (7,12–14) Longitudinal studies suggest that mental health problems persist over time in children born preterm. (15,16)

Intracranial abnormalities during the neonatal period are independent risk factors for psychiatric disorders later in life in children born preterm. (1,7,17) The risk for mental health problems may also be higher among infants born with foetal growth restriction with a number of studies reporting an increased risk for emotional, conduct and attention problems in children born small for gestational age compared with their peers born with weight appropriate for their gestation. (18,19)

Benefits

Long-term benefits

- Early identification of very preterm-born children with behaviour, emotional and attention problems and referral to healthcare services (12,20–22)
- Provides feedback and support to parents about their child's behavioural and emotional development (12,20–22)
- Improved management of mental health problems (consensus)
- Improved parental counselling (consensus)
- Improved healthcare planning (23)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including screening for mental health difficulties. (1,24)	A (High quality) B (High quality)	Patient information sheet
2. Parents receive standardised feedback about the results of their child's mental health screening in a language that is accessible to them. (7,12)	A (Moderate quality)	Parent feedback
3. Children identified at risk are offered referral to the appropriate healthcare service (with parental consent).	B (High quality)	Audit report
4. Parents are asked to consent to share the results of their child's screening tests with education services.	B (Moderate quality)	Parent consent
For healthcare professionals		
5. A unit guideline on follow-up programme including mental health is adhered to by all healthcare professionals.	B (High quality)	Guideline
6. Country specific test norms are applied when interpreting the results of screening tests. (25)	A (High quality)	Training documentation
7. Training on standardised mental health assessments, in which gestational age and first language are taken into account is attended by all responsible healthcare professionals. (5,14–16)	A (High quality) B (High quality)	Training documentation
8. Screening using standardised parent-report tools is carried out. (26,27)	A (High quality)	Audit report
For neonatal unit and follow-up team		
9. A unit guideline on follow-up programme including mental health is available and regularly updated.	B (High quality)	Guideline
10. A follow-up programme after discharge including mental health is funded and supported. (28,29)	A (High quality) B (Moderate quality)	Audit report
11. Follow-up rates are continuously monitored.	B (Moderate quality)	Audit report

12. Mental health outcomes are used for staff feedback.	B (Moderate quality)	Audit report
For hospital and follow-up team		
13. Training on standardised mental health assessments is ensured.	B (High quality)	Training documentation
For health service		
14. A national guideline on follow-up programme including mental health is available and regularly updated.	B (High quality)	Guideline
15. A follow-up service including mental-health is specified, funded and monitored.	B (Moderate quality)	Audit report

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
• Mental health assessment at transition to secondary/high-school age is offered. (1,30)	A (High quality)
• Parents are supported by a case manager (see Follow-up & continuing care). (30,31)	A (High quality)
• Provide incentives to attend follow-up programmes. (30)	A (High quality)
For healthcare professionals	
• Include standard autism screening. (32)	A (High quality)
For neonatal unit and follow-up team	
• Establish integrated electronic system with mental health follow-up provider to schedule follow-up visits.	B (Low quality)
For hospital and follow-up team	
• Dedicate assessment facility.	B (Moderate quality)
For health service	
• Develop a national network for benchmarking of follow-up outcomes. (33,34)	A (High quality)
• Include follow-up information on an electronic healthcare card.	B (Low quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about the importance of follow-up including mental health screening and of well-child visits for health screening that are available.

For healthcare professionals

- Attend training on standardised mental health assessments.
- Identify an appropriate parent-completed behavioural screening questionnaire that has nationally established norms for use.
- Institute a training programme and standard schedule of assessment.

- Establish a structure of communication with other healthcare institutions, providing follow-up care.

For neonatal unit and follow-up team

- Develop and implement a unit guideline on follow-up programme including mental health.
- Develop information material about importance of follow-up including mental health screening for parents.
- Establish a formal system of keeping track of families.
- Develop a structure of follow-up locally.

For hospital and follow-up team

- Support healthcare professionals to participate in training on standardised mental health assessments.
- Provide space and resources for follow-up assessments in clinics or postal/online.

For health service

- Develop and implement a national guideline on mental health follow-up services for the target group.

Source

1. Johnson S, Marlow N. Preterm birth and childhood psychiatric disorders. *Pediatr Res*. 2011 May;69(5 Pt 2):11R–8R.
2. Lindström K, Lindblad F, Hjern A. Psychiatric morbidity in adolescents and young adults born preterm: a Swedish national cohort study. *Pediatrics*. 2009 Jan;123(1):e47–53.
3. Hille ET, den Ouden AL, Saigal S, Wolke D, Lambert M, Whitaker A, et al. Behavioural problems in children who weigh 1000 g or less at birth in four countries. *Lancet Lond Engl*. 2001 May 26;357(9269):1641–3.
4. Farooqi A, Hägglöf B, Sedin G, Gothefors L, Serenius F. Mental health and social competencies of 10- to 12-year-old children born at 23 to 25 weeks of gestation in the 1990s: a Swedish national prospective follow-up study. *Pediatrics*. 2007 Jul;120(1):118–33.
5. Burnett AC, Anderson PJ, Cheong J, Doyle LW, Davey CG, Wood SJ. Prevalence of psychiatric diagnoses in preterm and full-term children, adolescents and young adults: a meta-analysis. *Psychol Med*. 2011 Dec;41(12):2463–74.
6. Scott MN, Taylor HG, Fristad MA, Klein N, Espy KA, Minich N, et al. Behavior disorders in extremely preterm/extremely low birth weight children in kindergarten. *J Dev Behav Pediatr JDBP*. 2012 Apr;33(3):202–13.
7. Johnson S, Hollis C, Kochhar P, Hennessy E, Wolke D, Marlow N. Psychiatric disorders in extremely preterm children: longitudinal finding at age 11 years in the EPICure study. *J Am Acad Child Adolesc Psychiatry*. 2010 May;49(5):453–463.e1.
8. Spittle AJ, Treyvaud K, Doyle LW, Roberts G, Lee KJ, Inder TE, et al. Early emergence of behavior and social-emotional problems in very preterm infants. *J Am Acad Child Adolesc Psychiatry*. 2009 Sep;48(9):909–18.
9. Reijneveld SA, de Kleine MJK, van Baar AL, Kollée LAA, Verhaak CM, Verhulst FC, et al. Behavioural and emotional problems in very preterm and very low birthweight infants at age 5 years. *Arch Dis Child Fetal Neonatal Ed*. 2006 Nov;91(6):F423–8.
10. Delobel-Ayoub M, Arnaud C, White-Koning M, Casper C, Pierrat V, Garel M, et al. Behavioral problems and cognitive performance at 5 years of age after very preterm birth: the EPIPAGE Study. *Pediatrics*. 2009 Jun;123(6):1485–92.

11. Delobel-Ayoub M, Kaminski M, Marret S, Burguet A, Marchand L, N'Guyen S, et al. Behavioral outcome at 3 years of age in very preterm infants: the EPIPAGE study. *Pediatrics*. 2006 Jun;117(6):1996–2005.
12. Treyvaud K, Doyle LW, Lee KJ, Roberts G, Lim J, Inder TE, et al. Social–Emotional Difficulties in Very Preterm and Term 2 Year Olds Predict Specific Social–Emotional Problems at the Age of 5 Years. *J Pediatr Psychol*. 2012 Aug 1;37(7):779–85.
13. Treyvaud K, Ure A, Doyle LW, Lee KJ, Rogers CE, Kidokoro H, et al. Psychiatric outcomes at age seven for very preterm children: rates and predictors. *J Child Psychol Psychiatry*. 2013 Jul;54(7):772–9.
14. Johnson S, Kochhar P, Hennessy E, Marlow N, Wolke D, Hollis C. Antecedents of Attention-Deficit/Hyperactivity Disorder Symptoms in Children Born Extremely Preterm. *J Dev Behav Pediatr JDBP*. 2016 May;37(4):285–97.
15. Breeman LD, Jaekel J, Baumann N, Bartmann P, Wolke D. Attention problems in very preterm children from childhood to adulthood: the Bavarian Longitudinal Study. *J Child Psychol Psychiatry*. 2016 Feb;57(2):132–40.
16. Gray RF, Indurkha A, McCormick MC. Prevalence, stability, and predictors of clinically significant behavior problems in low birth weight children at 3, 5, and 8 years of age. *Pediatrics*. 2004 Sep;114(3):736–43.
17. Ure AM, Treyvaud K, Thompson DK, Pascoe L, Roberts G, Lee KJ, et al. Neonatal brain abnormalities associated with autism spectrum disorder in children born very preterm. *Autism Res Off J Int Soc Autism Res*. 2016;9(5):543–52.
18. Indredavik MS, Vik T, Heyerdahl S, Kulseng S, Brubakk A-M. Psychiatric symptoms in low birth weight adolescents, assessed by screening questionnaires. *Eur Child Adolesc Psychiatry*. 2005 Jul;14(4):226–36.
19. Heinonen K, Räikkönen K, Pesonen A-K, Andersson S, Kajantie E, Eriksson JG, et al. Behavioural symptoms of attention deficit/hyperactivity disorder in preterm and term children born small and appropriate for gestational age: a longitudinal study. *BMC Pediatr*. 2010 Dec 15;10:91.
20. Johnson S, Hollis C, Marlow N, Simms V, Wolke D. Screening for childhood mental health disorders using the Strengths and Difficulties Questionnaire: the validity of multi-informant reports. *Dev Med Child Neurol*. 2014 May;56(5):453–9.
21. Briggs-Gowan MJ, Carter AS. Social-emotional screening status in early childhood predicts elementary school outcomes. *Pediatrics*. 2008 May;121(5):957–62.
22. Lemer C. Annual report of the Chief Medical Officer 2012: our children deserve better: prevention pays. 2013;
23. Johnson S, Gilmore C, Gallimore I, Jaekel J, Wolke D. The long-term consequences of preterm birth: what do teachers know? *Dev Med Child Neurol*. 2015 Jun;57(6):571–7.
24. Johnson S, Wolke D. Behavioural outcomes and psychopathology during adolescence [Internet]. 2013 [cited 2018 Jun 15]. Available from: <https://www.sciencedirect.com/science/article/pii/S0378378213000236>
25. Westera JJ, Houtzager BA, Overdiek B, van Wassenhaer AG. Applying Dutch and US versions of the BSID-II in Dutch children born preterm leads to different outcomes. *Dev Med Child Neurol*. 2008 Jun;50(6):445–9.
26. Johnson S, Wolke D, Marlow N. Outcome monitoring in preterm populations - Measures and methods. *Z Für Psychol J Psychol*. 2008 Jan 1;216(3):135–46.
27. Drotar D, Stancin T, Dworkin PH, Sices L, Wood S. Selecting developmental surveillance and screening tools. *Pediatr Rev*. 2008 Oct;29(10):e52-58.

28. Hille ETM, Elbertse L, Gravenhorst JB, Brand R, Verloove-Vanhorick SP, Dutch POPS-19 Collaborative Study Group. Nonresponse bias in a follow-up study of 19-year-old adolescents born as preterm infants. *Pediatrics*. 2005 Nov;116(5):e662-666.
29. Wolke D, Söhne B, Ohrt B, Riegel K. Follow-up of preterm children: important to document dropouts. *The Lancet*. 1995 Feb 18;345(8947):447.
30. Relton C, Strong M, Thomas KJ, Whelan B, Walters SJ, Burrows J, et al. Effect of Financial Incentives on Breastfeeding: A Cluster Randomized Clinical Trial. *JAMA Pediatr*. 2018 Feb 5;172(2):e174523.
31. Hüning BM, Reimann M, Beerenberg U, Stein A, Schmidt A, Felderhoff-Müser U. Establishment of a family-centred care programme with follow-up home visits: implications for clinical care and economic characteristics. *Klin Pädiatr*. 2012 Nov;224(7):431–6.
32. Kallioinen M, Eadon H, Murphy MS, Baird G, Guideline Committee. Developmental follow-up of children and young people born preterm: summary of NICE guidance. *BMJ*. 2017 10;358:j3514.
33. Wang CJ, McGlynn EA, Brook RH, Leonard CH, Piecuch RE, Hsueh SI, et al. Quality-of-care indicators for the neurodevelopmental follow-up of very low birth weight children: results of an expert panel process. *Pediatrics*. 2006 Jun;117(6):2080–92.
34. Mercier CE, Dunn MS, Ferrelli KR, Howard DB, Soll RF, Vermont Oxford Network ELBW Infant Follow-Up Study Group. Neurodevelopmental outcome of extremely low birth weight infants from the Vermont Oxford network: 1998-2003. *Neonatology*. 2010 Jun;97(4):329–38.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Johnson S, Jaekel J et al., European Standards of Care for Newborn Health: Mental Health. 2018.

Motor and neurological follow-up assessment

Hadders-Algra M, Vollmer B, Leemhuis AG, Wolke D

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care) and parents

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Standardised assessment of neurological status and motor development is conducted in the first two years and repeated at transition to school.

Rationale

The goal is to evaluate neuromotor development and identify those individuals who will benefit from additional support and intervention to optimise motor development and thereby improve social and cognitive development.

Very preterm infants and term born infants with neonatal neurological morbidity (e.g. hypoxic ischaemic encephalopathy, stroke) are at risk of adverse neuromotor outcomes, including Cerebral Palsy (CP). (1–5) CP impacts on activities and participation in daily life. (6) In industrialised countries the prevalence of CP in preterm infants is decreasing, whereas it remains fairly unchanged in term born infants. (7) The prevalence of minor neurological dysfunction and motor impairment in the absence of CP continues to be high. (8,9)

Early detection of neuromotor problems paves the way for early intervention and is important for counselling of parents. (10) There is evidence that early intervention is associated with a positive effect on early motor development. (11,12) In case of CP, early interventions also aim to prevent contractures and deformities.

During infancy frequent changes in neuromotor development occur. (13,14) This implies that infants at risk may gradually move to typical development, but also that infants may develop a deficit, such as CP. By the age of two years most children with CP will have been assigned a diagnosis. For less severe neuromotor disorders, it usually takes longer before they are recognisable. Regular monitoring during infancy and preschool age is warranted. Knowledge of neuromotor status in terms of minor neurological dysfunction also serves the early detection of developmental coordination disorder (DCD), attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and specific learning disorders. (15)

Benefits

Short-term benefits

N/A

Long-term benefits

- Better guidance for families (consensus)
- Reliable and early (before two years of age) identification of those who will develop significant neuromotor problems (Cerebral Palsy, CP) (16–18)
- Early referral to community services (consensus)

- Facilitated early multidisciplinary approach to management and early intervention for those who are in need of further input (12,19)
- Identification (at pre-school and school age) of those who develop motor difficulties in the absence of CP (20,21)
- Optimised social and cognitive development (12)
- Provides feedback to peri- and neonatal healthcare providers with regards to monitoring and improving quality of care (consensus)
- Promoted and improved healthy life style by encouragement of motor activities (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including screening for neuromotor developmental difficulties. (11,12,19)	A (High quality) B (High quality)	Patient information sheet
2. Parents are involved in early intervention, e.g., family-centred care. (22–25)	A (High quality)	Parent feedback
3. Parents receive standardised feedback about the results of their child's neuromotor health screening in a language that is accessible to them.	B (High quality)	Parent feedback
4. Children identified at risk are offered referral to the appropriate healthcare service and intervention is started in those infants with suspected abnormal neuromotor findings and motor delay (with parental consent). (11,12,22–25)	A (High quality) B (High quality)	Audit report
For healthcare professionals		
5. A guideline on follow-up programme including serial neuromotor assessment in the first two years (e.g. 3-6, 12, 24 months corrected age) and repeated at transition to school is adhered to by all healthcare professionals. (14,17,20,21,26)	A (High quality) B (High quality)	Audit report, guideline
6. Children with diagnosis of CP: from 12 months corrected age onwards at each follow-up appointment standardised assessment of CP according to Surveillance of Cerebral Palsy in Europe (SCPE) criteria (27,28), and from 24 months corrected age onwards	A (Moderate quality) B (High quality)	Audit report, guideline

assessment of functional level of gross motor function, manual ability and communication is ensured. (29–34)

- | | | | |
|----|---|--------------------------------------|------------------------|
| 7. | Training on standardised neuromotor assessment throughout infancy to school age (e.g. General Movement Assessment at 3-4 months corrected age) is attended by all responsible healthcare professionals. (16–18) | A (High quality)
B (High quality) | Training documentation |
|----|---|--------------------------------------|------------------------|

For neonatal unit, hospital, and follow-up team

- | | | | |
|-----|--|----------------------|------------------------|
| 8. | A guideline on the follow-up programme including neuromotor developmental health is available and regularly updated. | B (High quality) | Guideline |
| 9. | Follow-up programme after discharge including neuromotor developmental health is funded and supported. | B (Moderate quality) | Audit report |
| 10. | Follow-up rates are continuously monitored. | B (Moderate quality) | Audit report |
| 11. | Neuromotor developmental health outcomes are used for staff feedback. | B (Moderate quality) | Audit report |
| 12. | Training on standardised neuromotor assessments is ensured. | B (High quality) | Training documentation |
| 13. | Appropriate assessment facilities are provided. | B (High quality) | Audit report |

For health service

- | | | | |
|-----|---|------------------|--------------|
| 14. | A national guideline on follow-up programme including neuromotor assessment is available and regularly updated. | B (High quality) | Guideline |
| 15. | A follow-up service including neuromotor developmental health is specified, funded and monitored. | B (High quality) | Audit report |

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
Offer neuromotor follow-up into school age. (4)	A (High quality) B (Moderate quality)
For healthcare professionals	
N/A	
For neonatal unit, hospital, and follow-up team	
Integrate neonatal and neuromotor follow-up electronic systems.	B (Moderate quality)
For health service	
Monitor CP rates on a national basis. (7)	A (High quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about follow-up including neuromotor development assessments.

For healthcare professionals

- Start a service that uses parent reports using screening questionnaires (Ages and Stages Questionnaire (ASQ) or Parent Report of Children's Abilities-Revised (PARCA-R).
- Institute a training programme and standard schedule of assessment (screening or face-to-face assessments).
- If the findings of parent completed developmental screening questionnaires indicate delayed development in any of the domains, discuss referral to appropriate services for more detailed assessment with the family and, if appropriate, make sure it will be initiated.
- Attend training on standardised neuromotor and developmental assessments.
- Establish a structure of communication with other healthcare institutions providing follow-up.

For neonatal unit, hospital, and follow-up team

- Develop and implement a guideline on follow-up programme including neuromotor and developmental health.
- Develop information material on follow-up programme including neuromotor and developmental health.
- Establish a formal system of identifying infants who are eligible for follow-up and of keeping track of families.
- Develop a structure of standardised multidisciplinary follow-up locally.
- Establish a structure that facilitates early intervention in infants at high risk for neuromotor impairment.
- Support healthcare professionals to participate in training on standardised neuromotor and developmental health assessments.
- Provide space and resources for follow-up neuromotor developmental assessment in clinics or postal/online.

For health service

- Develop and implement a national guideline on follow-up programme including neuromotor and developmental health.

Source

1. de Graaf-Peters VB, Hadders-Algra M. Ontogeny of the human central nervous system: what is happening when? *Early Hum Dev.* 2006 Apr;82(4):257–66.
2. Volpe JJ. Brain injury in premature infants: a complex amalgam of destructive and developmental disturbances. *Lancet Neurol.* 2009 Jan;8(1):110–24.
3. Hielkema T, Hadders-Algra M. Motor and cognitive outcome after specific early lesions of the brain - a systematic review. *Dev Med Child Neurol.* 2016 Mar;58 Suppl 4:46–52.
4. de Kieviet JF, Piek JP, Aarnoudse-Moens CS, Oosterlaan J. Motor development in very preterm and very low-birth-weight children from birth to adolescence: a meta-analysis. *JAMA.* 2009 Nov 25;302(20):2235–42.
5. Natarajan G, Pappas A, Shankaran S. Outcomes in childhood following therapeutic hypothermia for neonatal hypoxic-ischemic encephalopathy (HIE). *Semin Perinatol.* 2016;40(8):549–55.
6. Himmelmann K, Uvebrant P. The panorama of cerebral palsy in Sweden. XI. Changing patterns in the birth-year period 2003-2006. *Acta Paediatr Oslo Nor 1992.* 2014 Jun;103(6):618–24.
7. Sellier E, Platt MJ, Andersen GL, Krägeloh-Mann I, De La Cruz J, Cans C, et al. Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003. *Dev Med Child Neurol.* 2016 Jan;58(1):85–92.
8. Ferrari F, Gallo C, Pugliese M, Guidotti I, Gavioli S, Coccolini E, et al. Preterm birth and developmental problems in the preschool age. Part I: minor motor problems. *J Matern-Fetal Neonatal Med Off J Eur Assoc Perinat Med Fed Asia Ocean Perinat Soc Int Soc Perinat Obstet.* 2012 Nov;25(11):2154–9.
9. Williams J, Lee KJ, Anderson PJ. Prevalence of motor-skill impairment in preterm children who do not develop cerebral palsy: a systematic review. *Dev Med Child Neurol.* 2010 Mar;52(3):232–7.
10. Novak I, Hines M, Goldsmith S, Barclay R. Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics.* 2012 Nov;130(5):e1285-1312.
11. Blauw-Hospers CH, Hadders-Algra M. A systematic review of the effects of early intervention on motor development. *Dev Med Child Neurol.* 2005;47(6):421–432.
12. Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database Syst Rev.* 2015 Nov 24;(11):CD005495.
13. Hadders-Algra M, Heineman KR, Bos AF, Middelburg KJ. The assessment of minor neurological dysfunction in infancy using the Touwen Infant Neurological Examination: strengths and limitations. *Dev Med Child Neurol.* 2010 Jan;52(1):87–92.
14. Janssen AJWM, Akkermans RP, Steiner K, de Haes OAM, Oostendorp RAB, Kollée LAA, et al. Unstable longitudinal motor performance in preterm infants from 6 to 24 months on the Bayley Scales of Infant Development--Second edition. *Res Dev Disabil.* 2011 Oct;32(5):1902–9.
15. Hadders-Algra M. Two distinct forms of minor neurological dysfunction: perspectives emerging from a review of data of the Groningen Perinatal Project. *Dev Med Child Neurol.* 2002 Aug;44(8):561–71.
16. Bosanquet M, Copeland L, Ware R, Boyd R. A systematic review of tests to predict cerebral palsy in young children. *Dev Med Child Neurol.* 2013 May;55(5):418–26.

17. Romeo DM, Ricci D, Brogna C, Mercuri E. Use of the Hammersmith Infant Neurological Examination in infants with cerebral palsy: a critical review of the literature. *Dev Med Child Neurol*. 2016 Mar;58(3):240–5.
18. Novak I, Morgan C, Adde L, Blackman J, Boyd RN, Brunstrom-Hernandez J, et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. *JAMA Pediatr*. 2017 Sep 1;171(9):897–907.
19. Hughes AJ, Redsell SA, Glazebrook C. Motor Development Interventions for Preterm Infants: A Systematic Review and Meta-analysis. *PEDIATRICS*. 2016 Oct 1;138(4):e20160147–e20160147.
20. Heineman KR, Hadders-Algra M. Evaluation of neuromotor function in infancy-A systematic review of available methods. *J Dev Behav Pediatr JDBP*. 2008 Aug;29(4):315–23.
21. Hadders-Algra M. The neuromotor examination of the preschool child and its prognostic significance. *Ment Retard Dev Disabil Res Rev*. 2005;11(3):180–8.
22. Vanderveen JA, Bassler D, Robertson CMT, Kirpalani H. Early interventions involving parents to improve neurodevelopmental outcomes of premature infants: a meta-analysis. *J Perinatol Off J Calif Perinat Assoc*. 2009 May;29(5):343–51.
23. Benzies KM, Magill-Evans JE, Hayden K, Ballantyne M. Key components of early intervention programs for preterm infants and their parents: a systematic review and meta-analysis. *BMC Pregnancy Childbirth*. 2013;13(Suppl 1):S10.
24. Morgan C, Darrah J, Gordon AM, Harbourne R, Spittle A, Johnson R, et al. Effectiveness of motor interventions in infants with cerebral palsy: a systematic review. *Dev Med Child Neurol*. 2016;58(9):900–9.
25. Hadders-Algra M, Boxum AG, Hielkema T, Hamer EG. Effect of early intervention in infants at very high risk of cerebral palsy: a systematic review. *Dev Med Child Neurol*. 2017;59(3):246–58.
26. Barnett AL, Guzzetta A, Mercuri E, Henderson SE, Haataja L, Cowan F, et al. Can the Griffiths scales predict neuromotor and perceptual-motor impairment in term infants with neonatal encephalopathy? *Arch Dis Child*. 2004 Jul;89(7):637–43.
27. Smithers-Sheedy H, Badawi N, Blair E, Cans C, Himmelmann K, Krägeloh-Mann I, et al. What constitutes cerebral palsy in the twenty-first century? *Dev Med Child Neurol*. 2014 Apr;56(4):323–8.
28. Surveillance of Cerebral Palsy in Europe. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE). *Dev Med Child Neurol*. 2000 Dec;42(12):816–24.
29. Rosenbaum PL, Walter SD, Hanna SE, Palisano RJ, Russell DJ, Raina P, et al. Prognosis for gross motor function in cerebral palsy: creation of motor development curves. *JAMA*. 2002 Sep 18;288(11):1357–63.
30. Palisano RJ, Cameron D, Rosenbaum PL, Walter SD, Russell D. Stability of the gross motor function classification system. *Dev Med Child Neurol*. 2006 Jun;48(6):424–8.
31. Gorter JW, Ketelaar M, Rosenbaum P, Helders PJM, Palisano R. Use of the GMFCS in infants with CP: the need for reclassification at age 2 years or older. *Dev Med Child Neurol*. 2009 Jan;51(1):46–52.
32. Nordstrand L, Eliasson A-C, Holmefur M. Longitudinal development of hand function in children with unilateral spastic cerebral palsy aged 18 months to 12 years. *Dev Med Child Neurol*. 2016;58(10):1042–8.
33. Eliasson A-C, Ullenhag A, Wahlström U, Krumlinde-Sundholm L. Mini-MACS: development of the Manual Ability Classification System for children younger than 4 years of age with signs of cerebral palsy. *Dev Med Child Neurol*. 2017;59(1):72–8.



34. Virella D, Pennington L, Andersen GL, Andrada M da G, Greitane A, Himmelmann K, et al. Classification systems of communication for use in epidemiological surveillance of children with cerebral palsy. *Dev Med Child Neurol*. 2016 Mar;58(3):285–91.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Hadders-Algra M, Vollmer B et al., European Standards of Care for Newborn Health: Motor and neurological follow-up assessment. 2018.

Parent mental health

Houtzager BA, Leemhuis AG, Wolke D, Virchez M

Target group

Infants born very preterm or those infants with risk factors (see preamble of Follow-up & continuing care), parents and their families

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Targeted screening of parental mental health is undertaken six months after discharge and at two years, during regular follow-up visits for the child.

Rationale

The experience of very preterm birth is stressful for parents. Mothers of high-risk infants (1–3) often suffer role loss (4) and are at increased risk for psychological and parenting stress. (1,5–7) During and after hospitalisation, parents may show symptoms of depression (8), posttraumatic stress disorder (PTSD) (3,6,9–12), or a combination of both. (13–15) There is a lack of information on fathers' distress. (16) The impact of preterm birth on parents is most evident in early childhood (17), particularly during the first six months. (4)

Parental distress may be associated with their infant's illness severity during the neonatal period (1,18), and lack of maternal role fulfillment. (4) Rehospitalisation (4) and concerns about the child's development (19) may be a further source of distress. Parental distress appears to be lessened under conditions of high social support (18,20), a higher level of education/SES, and in the presence of effective coping strategies and a positive developmental outcome for the child. (2) Low social support in combination with developmental difficulties in the child are particular risk factors. (18) Parent mental health is related to infant development and health, mediating child outcome (1,21), and parent mental health indirectly affects child development via parent-child interaction. (19) Post-NICU developmental interventions such as maternal infant transaction programme (MITP) (22,23) and infant behavioural assessment and intervention programme (IBA-IP) (24,25) seem to improve child cognitive development through sensitive parenting and improved parent-child interactions. (26) Post-NICU interventions that pay attention to parent mental health (22,27,28) seem effective in improving parent mental health.

Benefits

Short-term benefits

N/A

Long-term benefits

- Prepares parents for their potential emotional reactions after birth (consensus)
- Early identification and prompt treatment of parent mental health problems (11)
- Improved mental health support for at-risk families (see Follow-up & continuing care) (consensus)
- Improved parenting confidence (22,23)

- Facilitates parents capacity to support their child's development (9,22,23)
- Optimised neurodevelopmental outcomes (24,25,27,28)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals about potential emotional reactions to very preterm birth and the importance of assessment during regular follow-up visits in the first six months after discharge. (1–7,10,11,29)	A (High quality) B (High quality)	Clinical records, patient information sheet
2. Parents are supported by early intervention programmes if they are at risk for mental health problems (see Follow-up & continuing care). (27,28)	A (Moderate quality)	Guideline, parent feedback
For healthcare professionals		
3. A guideline on follow-up including parental mental health assessment is adhered to by all healthcare professionals.	B (High quality)	Guideline
4. Before each regular follow-up visit for the child at six months and at two years after discharge parents are screened for mental health problems, using locally available standardised screening tools such as Edinburgh Postnatal Depression Scale (EPDS), Hospital Anxiety and Depression Scale (HADS), or Distress Thermometer for Parents (DT-P). (30)	A (Moderate quality)	Guideline
5. Training on recognition of the clinical signs that are associated with mental health difficulties is attended by all responsible healthcare professionals.	B (High quality)	Training records
6. Parents with identified mental health problems after discharge are referred for locally available specialised mental health support.	B (High quality)	Clinical records
For neonatal unit, hospital, and follow-up team		
7. A guideline on follow-up including parental mental health assessment is available and regularly updated.	B (High quality)	Guideline

8. Training on recognition of the clinical signs that are associated with mental health difficulties is ensured.	B (High quality)	Training documentation
9. A follow-up team (nurse or pediatrician) is available and trained in addressing mental health issues in parents.	B (High quality)	Training documentation
For health service		
10. A national guideline on follow-up including parental mental health assessment is available and regularly updated.	B (High quality)	Guideline

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
N/A	
For healthcare professionals	
• Create awareness about the father's mental health.	B (High quality)
• Improve existing support programmes with extra modules for parent mental health specifically in at-risk/socioeconomically deprived populations. (25)	A (Moderate quality) B (Moderate quality)
For neonatal unit, hospital, and follow-up team	
• Establish a continuous chain of psychological support before and after discharge. (17)	A (Moderate quality)
• Facilitate home visits of targeted families, home visits after discharge for families at high medical and social risk. (22,27,28)	A (High quality)
For health service	
• Provide standardised information about parent mental health issues after very preterm birth (written, apps, E-health psychoeducational modules, instruction videos) in all European countries' languages. (9)	A (Moderate quality)
• Generate a greater understanding of the mental health needs of the father. (7,31)	A (High quality)
• Provide access to information about parent mental health in a child record.	B (High quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about potential emotional reactions to very preterm birth.
- Parents are asked by their paediatrician or family doctor at each follow-up visit after discharge how they are feeling.

For healthcare professionals

- Attend training on recognition of the clinical signs that are associated with mental health difficulties.
- Include inquiries about parent mental health and parental support during regular follow-up visits with doctors or nurses.
- Record whether parent mental health difficulties are suspected or detected and need to be monitored or treated.
- Inform the parents' family doctor if mental health screen positive.

For neonatal unit, hospital, and follow-up team

- Make a telephone call in the first weeks after discharge to check parental wellbeing, in the absence of a physical follow-up appointment.
- Develop and implement a unit guideline on follow-up including parental mental health.
- Develop information material about potential emotional reactions to very preterm birth.
- Organise information sharing about the family with follow-up team.
- Support healthcare professionals to participate in training on recognition of the clinical signs that are associated with mental health difficulties.
- Exchange/share information with agreement from parents.

For health service

- Develop and implement a national guideline on follow-up including parental mental health.

Source

1. Singer LT, Salvator A, Guo S, Collin M, Lilien L, Baley J. Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *JAMA*. 1999 Mar 3;281(9):799–805.
2. Saigal S, Pinelli J, Streiner DL, Boyle M, Stoskopf B. Impact of extreme prematurity on family functioning and maternal health 20 years later. *Pediatrics*. 2010 Jul;126(1):e81-88.
3. Pierrehumbert B, Nicole A, Muller-Nix C, Forcada-Guex M, Ansermet F. Parental post-traumatic reactions after premature birth: implications for sleeping and eating problems in the infant. *Arch Dis Child Fetal Neonatal Ed*. 2003 Sep;88(5):F400–4.
4. Miles MS, Holditch-Davis D, Schwartz TA, Scher M. Depressive symptoms in mothers of prematurely born infants. *J Dev Behav Pediatr JDBP*. 2007 Feb;28(1):36–44.
5. Meijssen D, Wolf M-J, Koldewijn K, Baar A van, Kok J. Maternal psychological distress in the first two years after very preterm birth and early intervention. *Early Child Dev Care*. 2011 Jan 1;181(1):1–11.
6. Ahlund S, Clarke P, Hill J, Thalange NKS. Post-traumatic stress symptoms in mothers of very low birth weight infants 2-3 years post-partum. *Arch Womens Ment Health*. 2009 Aug;12(4):261–4.
7. Ionio C, Colombo C, Brazzoduro V, Mascheroni E, Confalonieri E, Castoldi F, et al. Mothers and fathers in NICU: The impact of preterm birth on parental distress. *Eur J Psychol*. 2016 Nov 18;12(4):604–21.
8. Vigod SN, Villegas L, Dennis C-L, Ross LE. Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. *BJOG Int J Obstet Gynaecol*. 2010 Apr;117(5):540–50.
9. Melnyk BM, Crean HF, Feinstein NF, Fairbanks E. Maternal anxiety and depression after a premature infant's discharge from the neonatal intensive care unit: explanatory effects of the creating opportunities for parent empowerment program. *Nurs Res*. 2008 Dec;57(6):383–94.

10. Elklit A, Hartvig T, Christiansen M. Psychological Sequelae in Parents of Extreme Low and Very Low Birth Weight Infants. *J Clin Psychol Med Settings*. 2007 Sep 1;14(3):238–47.
11. Jotzo M, Poets CF. Helping parents cope with the trauma of premature birth: an evaluation of a trauma-preventive psychological intervention. *Pediatrics*. 2005 Apr;115(4):915–9.
12. Suttora C, Spinelli M, Monzani D. From prematurity to parenting stress: The mediating role of perinatal post-traumatic stress disorder. *Eur J Dev Psychol*. 2014 Jul 4;11(4):478–93.
13. Kersting A, Dorsch M, Wesselmann U, Lüdtorf K, Witthaut J, Ohrmann P, et al. Maternal posttraumatic stress response after the birth of a very low-birth-weight infant. *J Psychosom Res*. 2004 Nov;57(5):473–6.
14. Petit A-C, Eutrope J, Thierry A, Bednarek N, Aupetit L, Saad S, et al. Mother's Emotional and Posttraumatic Reactions after a Preterm Birth: The Mother-Infant Interaction Is at Stake 12 Months after Birth. *PloS One*. 2016;11(3):e0151091.
15. Garfield L, Holditch-Davis D, Carter CS, McFarlin BL, Schwertz D, Seng JS, et al. Risk factors for postpartum depressive symptoms in low-income women with very low-birth-weight infants. *Adv Neonatal Care Off J Natl Assoc Neonatal Nurses*. 2015 Feb;15(1):E3-8.
16. Wong O, Nguyen T, Thomas N, Thomson-Salo F, Handrinos D, Judd F. Perinatal mental health: Fathers - the (mostly) forgotten parent. *Asia-Pac Psychiatry Off J Pac Rim Coll Psychiatr*. 2016 Dec;8(4):247–55.
17. Treyvaud K. Parent and family outcomes following very preterm or very low birth weight birth: a review. *Semin Fetal Neonatal Med*. 2014 Apr;19(2):131–5.
18. Singer LT, Fulton S, Kirchner HL, Eisengart S, Lewis B, Short E, et al. Longitudinal predictors of maternal stress and coping after very low-birth-weight birth. *Arch Pediatr Adolesc Med*. 2010 Jun;164(6):518–24.
19. Korja R, Maunu J, Kirjavainen J, Savonlahti E, Haataja L, Lapinleimu H, et al. Mother-infant interaction is influenced by the amount of holding in preterm infants. *Early Hum Dev*. 2008 Apr;84(4):257–67.
20. Poehlmann J, Schwichtenberg AJM, Bolt D, Dilworth-Bart J. Predictors of depressive symptom trajectories in mothers of preterm or low birth weight infants. *J Fam Psychol JFP J Div Fam Psychol Am Psychol Assoc Div 43*. 2009 Oct;23(5):690–704.
21. Feldman R, Granat A, Pariente C, Kanety H, Kuint J, Gilboa-Schechtman E. Maternal depression and anxiety across the postpartum year and infant social engagement, fear regulation, and stress reactivity. *J Am Acad Child Adolesc Psychiatry*. 2009 Sep;48(9):919–27.
22. Kaaresen PI, Rønning JA, Ulvund SE, Dahl LB. A randomized, controlled trial of the effectiveness of an early-intervention program in reducing parenting stress after preterm birth. *Pediatrics*. 2006 Jul;118(1):e9-19.
23. Kaaresen PI, Rønning JA, Tunby J, Nordhov SM, Ulvund SE, Dahl LB. A randomized controlled trial of an early intervention program in low birth weight children: outcome at 2 years. *Early Hum Dev*. 2008 Mar;84(3):201–9.
24. Koldewijn K, van Wassenae A, Wolf M-J, Meijssen D, Houtzager B, Beelen A, et al. A neurobehavioral intervention and assessment program in very low birth weight infants: outcome at 24 months. *J Pediatr*. 2010 Mar;156(3):359–65.
25. Koldewijn K, Wolf M-J, van Wassenae A, Beelen A, de Groot IJM, Hedlund R. The Infant Behavioral Assessment and Intervention Program to support preterm infants after hospital discharge: a pilot study. *Dev Med Child Neurol*. 2005 Feb;47(2):105–12.
26. van Wassenae-Leemhuis AG, Jeukens-Visser M, van Hus JWP, Meijssen D, Wolf M-J, Kok JH, et al. Rethinking preventive post-discharge intervention programmes for very preterm infants and their parents. *Dev Med Child Neurol*. 2016 Mar;58 Suppl 4:67–73.



27. Nordhov SM, Rønning JA, Ulvund SE, Dahl LB, Kaaresen PI. Early intervention improves behavioral outcomes for preterm infants: randomized controlled trial. *Pediatrics*. 2012 Jan;129(1):e9–16.
28. Spittle AJ, Anderson PJ, Lee KJ, Ferretti C, Eeles A, Orton J, et al. Preventive care at home for very preterm infants improves infant and caregiver outcomes at 2 years. *Pediatrics*. 2010 Jul;126(1):e171-178.
29. Holditch-Davis D, Santos H, Levy J, White-Traut R, O'Shea TM, Geraldo V, et al. Patterns of psychological distress in mothers of preterm infants. *Infant Behav Dev*. 2015 Nov;41:154–63.
30. van Oers HA, Schepers SA, Grootenhuis MA, Haverman L. Dutch normative data and psychometric properties for the Distress Thermometer for Parents. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil*. 2017;26(1):177–82.
31. Ramchandani P, Psychogiou L. Paternal psychiatric disorders and children's psychosocial development. *Lancet Lond Engl*. 2009 Aug 22;374(9690):646–53.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citations

EFCNI, Houtzager BA, Leemhuis AG et al., European Standards of Care for Newborn Health: Parental mental health. 2018.



Peer and sibling relationships

Vaillancourt T, Hymel S, Wolke D, Leemhuis AG

Target group

Infants born very preterm or those infants with risk factors (see preamble Follow-up & continuing care, and standard on Cognitive development) and parents

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Peer and sibling relationships are evaluated as part of a standard follow-up programme.

Rationale

The goal is to ensure that children who have problems in peer relationships are identified and their needs met.

Belonging is a fundamental, biologically-based, human need that operates across the lifespan. (1) As children grow up, peers contribute increasingly to both belonging and socialisation. (2) Children who experience difficulties in peer relationships, including those who are bullied, excluded, rejected, and/or disliked by peers, are at significant risk for major developmental difficulties, including mental and physical health problems, academic challenges, absenteeism and truancy. (3,4) The negative impact of poor peer relations is both far reaching, touching virtually all aspects of functioning, and enduring, impacting health and well-being long after the poor treatment from peers has ended. (5,6) Very preterm children are especially vulnerable for experiencing peer difficulties. (7,8) Their increased risk for altered cognitive and physical development contributes to difficulties with interpersonal relationships (7,8) and increases victimisation by peers, even when they do not have obvious motor, cognitive, or sensory issues. (9) Peer relationships characterised by high levels of intimacy and prosocial behaviour play a positive role in children's health and well-being. (10) Friendships (11) and sibling relationships (12) serve as powerful protective factors against peer victimisation and help mitigate the negative effects of peer abuse.

Using a comprehensive, developmentally appropriate, short screening assessment of socio-emotional development and peer relationships, an annual screening for peer relationship problems from school entry should be developed. (13,14) Children with peer relationship difficulties should be referred to appropriate health and education teams.

Benefits

Short-term benefits

N/A

Long-term benefits

- Early identification and referral of very preterm children with mental and physical health problems stemming from peer and sibling relationship problems (7,8)
- Provides feedback about peer and sibling relationships (15)
- Provides support and advocacy (3)

- Reduced risk of secondary mental health, physical health, and academic problems associated with peer and sibling relationship problems (3,13–15)
- Increased social integration (3,13,14)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For children, parents and family		
1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including peer and sibling relationships.	B (High quality)	Patient information sheet
2. Children receive screening for peer and sibling relationship problems. (16–20)	A (High quality)	Audit report, parent feedback
3. Parents of children identified at risk for peer and sibling relationship difficulties receive help about appropriate interventions and monitoring of progress. (13–15)	A (High quality)	Parent feedback
For healthcare professionals		
4. A unit guideline on follow-up including peer and sibling relationships is adhered to by all healthcare professionals.	B (High quality)	Guideline
5. Training on peer and sibling relationships is attended by all responsible healthcare professionals. (16–18)	A (High quality) B (High quality)	Training documentation
6. Screening for peer and sibling relationship problems using standardised tools is carried out. (16–18)	B (Moderate quality)	Audit report
For neonatal unit and follow-up team		
7. A unit guideline on follow-up including peer and sibling relationships is available and regularly updated.	B (High quality)	Guideline
For hospital and follow-up team		
8. Training on peer and sibling relationships is ensured.	B (High quality)	Training documentation
For health service		
9. A national guideline on follow-up including peer and sibling relationships is available and regularly updated.	B (High quality)	Guideline

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
Easily available information on peer and sibling relations for families are developed.	B (Moderate quality)
For healthcare professionals	
Identify precursors of peer and sibling relationship problems. (3,21)	A (High quality)
For neonatal unit and follow-up team	
N/A	
For hospital and follow-up team	
N/A	
For health service	
Assess the impact of healthcare providers screening for social development and peer and sibling relations.	B (Low quality)

Getting started

Initial steps
For parents and family
Parents are informed by healthcare professionals about peer and sibling relationships of preterm born infants.
For healthcare professionals
- Attend training on the evaluation of peer and sibling relationships. - Raise awareness of the importance of peer relationships for developmental outcomes.
For neonatal unit and follow-up team
- Develop and implement a unit guideline on follow-up including peer and sibling relationships. - Develop information material about peer and sibling relationships of preterm born infants for parents.
For hospital and follow-up team
Support healthcare professionals to participate in training on peer and sibling relationships.
For health service
Develop and implement a national guideline on follow-up including peer and sibling relationships.

Description

The importance of social relationships in health and well-being is underscored by a meta-analytic review demonstrating a “50% increase in odds of survival as a function of social relationships”. (22) Social relationships include social network integration, received social support, and perceived social support. Although the quality of caregiver-child relationships has long been emphasised in the promotion of positive cognitive, emotional, and behavioural responses (23), there is strong and growing evidence that peers are an important developmental context that also impacts adaptation across the life span. Bullying (being the target of repeated, intentional

abuse by peers who hold more power) is especially problematic for children's health and development. Bullying begins early in life, when children enter peer groups, contributes to loneliness, sadness, and anger, and is predictive of future peer relationship problems. (24) Bullying peaks around early adolescence (age 10-12) and declines in late adolescence, but never goes away completely. (25,26)

To date, healthcare providers have been at the periphery of efforts to prevent, educate, and address peer relation difficulties despite being important stakeholders in promoting child health. (18,27) Given that poor peer relationships are associated with significant health problems and positive social relationships are associated with wellness, the role of healthcare providers in promoting positive social interpersonal relationships is vital. Many children report being hesitant to disclose problematic peer interactions like bullying to adults because they feel adults will be ineffective, but there is emerging evidence that children would not only disclose to physicians, but that they want physicians to ask them about their peer relationships. (16) Although healthcare providers may not directly observe such interpersonal difficulties, they are often in a position to treat the symptoms of the problem and can identify root causes and contributing factors, including difficulties with peer relationships. Healthcare providers can help children by (a) validating that their social development is an important health issue worthy of attention, (b) being aware of symptoms and signs of peer relationship problems which may prove important for effective treatment of associated conditions, and (c) screening for peer relationship difficulties in clinical settings and intervene if and when needed.

Source

1. Baumeister RF, Leary MR. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychol Bull.* 1995 May;117(3):497–529.
2. Harris JR. Where Is the Child's Environment? A Group Socialization Theory of Development. *Psychol Rev.* 1995 Jul;102(3):458–89.
3. McDougall P, Vaillancourt T. Long-term adult outcomes of peer victimization in childhood and adolescence: Pathways to adjustment and maladjustment. *Am Psychol.* 2015;70(4):300–10.
4. National Academies of Sciences E. Preventing Bullying Through Science, Policy, and Practice [Internet]. Washington, DC: The National Academies Press; 2016 [cited 2018 May 16]. Available from: <https://www.nap.edu/catalog/23482/preventing-bullying-through-science-policy-and-practice>
5. Lereya ST, Copeland WE, Costello JE, Wolke D. Adult mental health consequences of peer bullying and maltreatment in childhood: two cohorts in two countries - *The Lancet Psychiatry.* 2015 Jun;2(6):p524-531.
6. Takizawa R, Maughan B, Arseneault L. Adult health outcomes of childhood bullying victimization: evidence from a five-decade longitudinal British birth cohort. *Am J Psychiatry.* 2014 Jul;171(7):777–84.
7. Day KL, Schmidt LA, Vaillancourt T, Saigal S, Boyle MH, Van Lieshout RJ. Long-term Psychiatric Impact of Peer Victimization in Adults Born at Extremely Low Birth Weight. *Pediatrics.* 2016 Mar;137(3):e20153383.
8. Day KL, Van Lieshout RJ, Vaillancourt T, Saigal S, Boyle MH, Schmidt LA. Long-term effects of peer victimization on social outcomes through the fourth decade of life in individuals born at normal or extremely low birthweight. *Br J Dev Psychol.* 2017 Sep;35(3):334–48.
9. Nadeau L, Tessier R, Lefebvre F, Robaey P. Victimization: a newly recognized outcome of prematurity. *Dev Med Child Neurol.* 2004 Aug;46(8):508–13.



10. Berndt TJ. Friendship Quality and Social Development: Curr Dir Psychol Sci [Internet]. 2016 Jun 22 [cited 2018 May 16]; Available from: <http://journals.sagepub.com/doi/pdf/10.1111/1467-8721.00157>
11. Hodges EV, Boivin M, Vitaro F, Bukowski WM. The power of friendship: protection against an escalating cycle of peer victimization. *Dev Psychol*. 1999 Jan;35(1):94–101.
12. Lamarche V, Brendgen M, Boivin M, Vitaro F, Périusse D, Dionne G. Do Friendships and Sibling Relationships Provide Protection against Peer Victimization in a Similar Way? *Soc Dev*. 2006 Aug 1;15(3):373–93.
13. Taylor RD, Oberle E, Durlak JA, Weissberg RP. Promoting Positive Youth Development Through School-Based Social and Emotional Learning Interventions: A Meta-Analysis of Follow-Up Effects. *Child Dev*. 2017;88(4):1156–71.
14. Domitrovich CE, Durlak JA, Staley KC, Weissberg RP. Social-Emotional Competence: An Essential Factor for Promoting Positive Adjustment and Reducing Risk in School Children. *Child Dev*. 2017;88(2):408–16.
15. Jones DE, Greenberg M, Crowley M. Early Social-Emotional Functioning and Public Health: The Relationship Between Kindergarten Social Competence and Future Wellness. *Am J Public Health*. 2015 Jul 16;105(11):2283–90.
16. Scott E, Dale J, Russell R, Wolke D. Young people who are being bullied – do they want general practice support? *BMC Fam Pract*. 2016 Aug 22;17:116.
17. Lamb J, Pepler DJ, Craig W. Approach to bullying and victimization. *Can Fam Physician*. 2009 Apr;55(4):356–60.
18. Moreno MA, Vaillancourt T. The Role of Health Care Providers in Cyberbullying. *Can J Psychiatry*. 2017 Jun;62(6):364–7.
19. Wolke D, Baumann N, Strauss V, Johnson S, Marlow N. Bullying of preterm children and emotional problems at school age: cross-culturally invariant effects. *J Pediatr*. 2015 Jun;166(6):1417–22.
20. Gladden RM. Bullying Surveillance among Youths: Uniform Definitions for Public Health and Recommended Data Elements. Version 1.0. *Cent Dis Control Prev*. 2014;
21. Wolke D, Lereya T, Tippett N. Individual and social determinants of bullying and cyberbullying. In: Vollink T, Dhue F, McGuckin C, editors. *Cyberbullying - From theory to intervention*. London: Routledge; 2016. p. 26–53.
22. Bowlby J. Attachment and loss. 2nd ed. New York: Basic Books; 1999. 1 p.
23. Social Relationships and Mortality Risk: A Meta-analytic Review [Internet]. [cited 2018 May 16]. Available from: <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000316>
24. Barker ED, Boivin M, Brendgen M, Fontaine N, Arseneault L, Vitaro F, et al. Predictive validity and early predictors of peer-victimization trajectories in preschool. *Arch Gen Psychiatry*. 2008 Oct;65(10):1185–92.
25. Cook CR, Williams KR, Guerra NG, Kim TE, Sadek S. Predictors of bullying and victimization in childhood and adolescence: A meta-analytic investigation. *Sch Psychol Q*. 2010;25(2):65–83.
26. Vaillancourt T, Trinh V, McDougall P, Duku E, Cunningham L, Cunningham C, et al. Optimizing Population Screening of Bullying in School-Aged Children. *J Sch Violence*. 2010 Jun 29;9(3):233–50.
27. Vaillancourt T, Faris R, Mishna F. Cyberbullying in Children and Youth: Implications for Health and Clinical Practice. *Can J Psychiatry Rev Can Psychiatr*. 2017 Jun;62(6):368–73.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Vaillancourt T, Hymel S et al., European Standards of Care for Newborn Health: Peer and sibling relationships. 2018.



Post-discharge responsive parenting programmes

Koldewijn K, Wolf MJ, Pierrat V, Leemhuis AG, Wolke D

Target group

Infants born very preterm or those infants with risk factors (see preamble of Follow-up & continuing care), parents and their families

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

All very preterm infants and their families are offered preventive responsive parenting support after discharge home.

Rationale

The strong influence of early experience and environmental influences on brain architecture makes the first years of life a period of both opportunity and vulnerability for development. (1)

Particularly the consistency of responsive interactions between children and their parents is of pivotal influence, because it affects both the developmental process of the infant's brain, as well as the adult's transition to parenthood. (1,2)

In very preterm parent-infant dyads, difficulties in responsive interactions may easily occur, as more than half have multiple mild developmental problems. The infants may be less responsive and explorative, and have more feeding and sleeping difficulties and/or experience more stress and disorganisation. (3) The problems may be bidirectional, as risk factors like depression or chronic stress are more common in parents of preterm infants and may impede the parental neurobiological and psychological changes that support responsive parenting under normal conditions. (2,4)

Consequently, very preterm infants may need more sensitive/responsive parenting, at a time when the parents themselves are often under additional stress. The first postnatal year offers a window of opportunity, because at this early stage, the brains of both the preterm infant and parent are particularly receptive to interventions that address responsive parenting. (2,5) Therefore, supporting both parents and the parent-child relationship is recommended ('two generation approach') to enhance infant developmental opportunities. (6)

Benefits

Long-term benefits

- Improved motor and cognitive development, behaviour, self-regulation, and wellbeing (7–15)
- Less referral for paramedical support (7–15)
- Improved health, sleeping, eating and early communication between infant and parent (consensus)
- Improved parental wellbeing and parent-child interactions (12,16–20)
- Less parenting stress (19,21,22)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals about responsive parenting support after discharge. (23–27)	A (High quality) B (High quality)	Patient information sheet
2. Intervention to support the parent-infant relationship starts in hospital and continues in the home environment (see Infant- & family-centred developmental care). (1,2,23–27)	B (High quality)	Guideline, parent feedback
3. Parents contribute to reports of developmental progress as equal partners with healthcare professionals.	B (Moderate quality)	Clinical records, parent feedback
For healthcare professionals		
4. A guideline on early post-discharge responsive parenting programmes is adhered to by all healthcare professionals.	B (High quality)	Guideline
5. Continuous professional development in a responsive parenting programme, based on evidence or best practice is attended by all responsible healthcare professionals. (7,10,23–27)	A (High quality) B (High quality)	Training documentation
For neonatal unit, hospital, and follow-up team		
6. A guideline on early post-discharge responsive parenting programmes is available and regularly updated.	B (High quality)	Guideline
7. Continuous professional development in a responsive parenting programme, based on evidence or best practice is ensured. (7,10,23–27)	A (High quality) B (High quality)	Training documentation
For health service		
8. A national guideline on early post-discharge responsive parenting programmes is available and regularly updated.	B (High quality)	Guideline
9. Appropriate funding for early post-discharge responsive parenting programmes is provided. (23–27)	B (High quality)	Audit report

10. Uptake of early post-discharge responsive parenting programmes is monitored.	B (High quality)	Audit report
--	------------------	--------------

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
Consider post discharge parenting programmes for other vulnerable groups of children, starting with moderately preterm infants. (23–27)	B (High quality)
For healthcare professionals	
Consider extensions of evidence-based post-discharge intervention programmes at other critical periods in the development of a preterm child. (23–29)	A (Moderate quality) B (High quality)
For neonatal unit, hospital, and follow-up team	
Include a minimum dataset in the follow-up programmes to better assess the impact of post-discharge intervention programmes on development.	B (Moderate quality)
For health service	
Encourage studies that develop more individualised responsive parenting programmes. (30)	B (Moderate quality)

Getting started

Initial steps
For parents and family
Parents are informed by healthcare professionals about anticipatory guidance on the transition to parenthood and are asked about their own wellbeing.
For healthcare professionals
Attend training on child development, parenting influences, and responsive parenting interventions.
For neonatal unit, hospital, and follow-up team
- Develop and implement a guideline on follow-up including responsive parenting programmes for parents of very preterm infants. - Develop information material on positive responsive parenting. - Assess the availability of post-discharge intervention programmes and create a network between units to support parents. - Support healthcare professionals to participate in training on child development, parenting influences, and responsive parenting interventions. - Ensure appropriate healthcare professionals have extra time and knowledge needed to support parents and infants in responsive parenting programmes.
For health service
- Develop and implement a national guideline on follow-up including responsive parenting programmes for parents of very preterm infants. - Raise awareness about the critical early years for infant development, and the need to give positive support to parents of preterm born children.

- Encourage health systems and stakeholders to invest in training in responsive parenting.

Description

Key features of programmes to support parenting are:

Parents receive inspiring information on the child's behavioral signals and small next developmental steps.

- Pro-active information is known as a strong protective factor. Strengthening parental understanding of environmental influences on early brain development, providing inspiring information on the infant's behavioral signals and taking small next steps may help parents in their mediating task, these may promote appropriate developmental expectations.
- In addition, knowledge of the sensitive periods in brain development enables parents to support their child's age-specific development and needs at any time in order to thrive in an optimal way.

Parents are supported through 'strength-based' intervention suggestions.

- Responsive parenting programmes that have a strength-based approach focus on reinforcing the strengths and resources that already exist in the infant and parent. A positive approach helps parents to respect and enjoy their child's behavioral efforts and skills, and gives the satisfaction to be able to help their child; it may support parental self-efficacy and confidence in themselves and their child.

Parents learn about the transition to parenthood and their own wellbeing.

- Pro-active information about the transition to parenthood and psycho-education during the sensitive period of the neurobiological transition to parenthood may enhance a positive feed-forward loop: parental wellbeing supports parents' sensitivity and responsive interactions, which is reflected in more structural growth and activity in the reward and motivational circuits in their brain. This appears significant, as these changes are also associated with more sensitive and caring maternal and paternal behaviors.

Source

1. Timing_Quality_Early_Experiences-1.pdf [Internet]. [zitiert 22. Juni 2018]. Verfügbar unter: http://developingchild.harvard.edu/wp-content/uploads/2007/05/Timing_Quality_Early_Experiences-1.pdf
2. Watamura S, Kim P. Two Open Windows: Infant and Parent Neurobiologic Change [Internet]. The Aspen Institute; 2015 [zitiert 16. Juli 2018]. Verfügbar unter: <https://ascend.aspeninstitute.org/resources/two-open-windows-infant-and-parent-neurobiologic-change-2/>
3. Bilgin A, Wolke D. Regulatory Problems in Very Preterm and Full-Term Infants Over the First 18 Months. J Dev Behav Pediatr JDBP. Mai 2016;37(4):298–305.
4. Pace CC, Spittle AJ, Molesworth CM-L, Lee KJ, Northam EA, Cheong JLY, u. a. Evolution of Depression and Anxiety Symptoms in Parents of Very Preterm Infants During the Newborn Period. JAMA Pediatr. 1. September 2016;170(9):863–70.

5. Spittle A, Treyvaud K. The role of early developmental intervention to influence neurobehavioral outcomes of children born preterm. *Semin Perinatol.* 2016;40(8):542–8.
6. Shonkoff JP, Fisher PA. Rethinking evidence-based practice and two-generation programs to create the future of early childhood policy. *Dev Psychopathol.* November 2013;25(4 Pt 2):1635–53.
7. Koldewijn K, van Wassenauer A, Wolf M-J, Meijssen D, Houtzager B, Beelen A, u. a. A neurobehavioral intervention and assessment program in very low birth weight infants: outcome at 24 months. *J Pediatr.* März 2010;156(3):359–65.
8. Van Hus J, Jeukens-Visser M, Koldewijn K, Holman R, Kok JH, Nollet F, u. a. Early intervention leads to long-term developmental improvements in very preterm infants, especially infants with bronchopulmonary dysplasia. *Acta Paediatr Oslo Nor* 1992. Juli 2016;105(7):773–81.
9. Van Hus JWP, Jeukens-Visser M, Koldewijn K, Geldof CJA, Kok JH, Nollet F, u. a. Sustained developmental effects of the infant behavioral assessment and intervention program in very low birth weight infants at 5.5 years corrected age. *J Pediatr.* Juni 2013;162(6):1112–9.
10. Nordhov SM, Rønning JA, Dahl LB, Ulvund SE, Tunby J, Kaarsen PI. Early intervention improves cognitive outcomes for preterm infants: randomized controlled trial. *Pediatrics.* November 2010;126(5):e1088-1094.
11. Landsem IP, Handegård BH, Ulvund SE, Tunby J, Kaarsen PI, Rønning JA. Does An Early Intervention Influence Behavioral Development Until Age 9 in Children Born Prematurely? *Child Dev.* Juli 2015;86(4):1063–79.
12. Landsem IP, Handegård BH, Ulvund SE, Kaarsen PI, Rønning JA. Early intervention influences positively quality of life as reported by prematurely born children at age nine and their parents; a randomized clinical trial. *Health Qual Life Outcomes.* 22. Februar 2015;13.
13. Wu Y-C, Hsieh W-S, Hsu C-H, Chang J-H, Chou H-C, Hsu H-C, u. a. Intervention effects on emotion regulation in preterm infants with very low birth weight: A randomized controlled trial. *Res Dev Disabil.* Januar 2016;48:1–12.
14. Habersaat S, Pierrehumbert B, Forcada-Guex M, Nessi J, Ansermet F, Müller-Nix C, u. a. Early stress exposure and later cortisol regulation: Impact of early intervention on mother–infant relationship in preterm infants. *Psychol Trauma Theory Res Pract Policy.* 2014;6(5):457–64.
15. Olafsen KS, Rønning JA, Handegård BH, Ulvund SE, Dahl LB, Kaarsen PI. Regulatory competence and social communication in term and preterm infants at 12 months corrected age. Results from a randomized controlled trial. *Infant Behav Dev.* Februar 2012;35(1):140–9.
16. Kaarsen PI, Rønning JA, Tunby J, Nordhov SM, Ulvund SE, Dahl LB. A randomized controlled trial of an early intervention program in low birth weight children: outcome at 2 years. *Early Hum Dev.* März 2008;84(3):201–9.
17. Landsem IP, Handegård BH, Tunby J, Ulvund SE, Rønning JA. Early intervention program reduces stress in parents of preterms during childhood, a randomized controlled trial. *Trials.* 4. Oktober 2014;15:387.
18. Borghini A, Habersaat S, Forcada-Guex M, Nessi J, Pierrehumbert B, Ansermet F, u. a. Effects of an early intervention on maternal post-traumatic stress symptoms and the quality of mother-infant interaction: the case of preterm birth. *Infant Behav Dev.* November 2014;37(4):624–31.
19. Ravn IH, Smith L, Lindemann R, Smeby NA, Kyno NM, Bunch EH, u. a. Effect of early intervention on social interaction between mothers and preterm infants at 12 months of age: a randomized controlled trial. *Infant Behav Dev.* April 2011;34(2):215–25.
20. Meijssen D, Wolf M-J, Koldewijn K, Houtzager BA, van Wassenauer A, Tronick E, u. a. The effect of the Infant Behavioral Assessment and Intervention Program on mother-infant interaction after very preterm birth. *J Child Psychol Psychiatry.* November 2010;51(11):1287–95.



21. Meijssen DE, Wolf MJ, Koldewijn K, van Wassenae AG, Kok JH, van Baar AL. Parenting stress in mothers after very preterm birth and the effect of the Infant Behavioural Assessment and Intervention Program. *Child Care Health Dev.* März 2011;37(2):195–202.
22. Nordhov SM, Kaaresen PI, Rønning JA, Ulvund SE, Dahl LB. A randomized study of the impact of a sensitizing intervention on the child-rearing attitudes of parents of low birth weight preterm infants. *Scand J Psychol.* Oktober 2010;51(5):385–91.
23. The Importance of caregiver-child interactions for the survival and healthy development of young children | Attachment Theory | Caregiver [Internet]. Scribd. [zitiert 22. Juni 2018]. Verfügbar unter: <https://www.scribd.com/document/117815507/The-Importance-of-caregiver-child-interactions-for-the-survival-and-healthy-development-of-young-children>
24. March of Dimes, PMNCH, Save the Children, WHO. Born Too Soon: The Global Action Report on Preterm Birth. [Internet]. World Health Organization; 2012. Verfügbar unter: http://www.who.int/pmnch/media/news/2012/201204_borntoosoon-report.pdf
25. UNICEF - 2015 - For every child, a fair chance the promise of equ.pdf [Internet]. [zitiert 22. Juni 2018]. Verfügbar unter: https://www.unicef.org/publications/files/For_every_child_a_fair_chance.pdf
26. Building Core Capabilities for Life.pdf [Internet]. [zitiert 22. Juni 2018]. Verfügbar unter: <https://46y5eh11fhgw3ve3ytpwxt9r-wpengine.netdna-ssl.com/wp-content/uploads/2016/03/Building-Core-Capabilities-for-Life.pdf>
27. Britto PR, Lye SJ, Proulx K, Yousafzai AK, Matthews SG, Vaivada T, u. a. Nurturing care: promoting early childhood development. *The Lancet.* 7. Januar 2017;389(10064):91–102.
28. Landry SH, Smith KE, Swank PR, Guttentag C. A Responsive Parenting Intervention: The Optimal Timing Across Early Childhood For Impacting Maternal Behaviors And Child Outcomes. *Dev Psychol.* September 2008;44(5):1335–53.
29. Flierman M, Koldewijn K, Meijssen D, van Wassenae-Leemhuis A, Aarnoudse-Moens C, van Schie P, u. a. Feasibility of a Preventive Parenting Intervention for Very Preterm Children at 18 Months Corrected Age: A Randomized Pilot Trial. *J Pediatr.* September 2016;176:79-85.e1.
30. From Best Practices to Breakthrough Impacts.pdf [Internet]. [zitiert 22. Juni 2018]. Verfügbar unter: https://46y5eh11fhgw3ve3ytpwxt9r-wpengine.netdna-ssl.com/wp-content/uploads/2016/05/From_Best_Practices_to_Breakthrough_Impacts-4.pdf

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Koldewijn K, Wolf MJ et al., European Standards of Care for Newborn Health: Post-discharge responsive parenting programmes. 2018.



Reproductive counselling

Prefumo F, Johnson MR, Leemhuis AG, Wolke D

Target group

Mothers of very preterm infants and their partners

User group

Healthcare professionals, perinatal and neonatal units, hospitals, health services, and follow-up teams

Statement of Standard

Mothers of infants born very preterm or after 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.

Rationale

The goal is to assess and evaluate the risk of recurrence of preterm birth or other severe pregnancy complications after birth of a high-risk infant.

Compared to the general population, women with a previous preterm delivery have an increased risk of preterm delivery in future pregnancies. (1,2) This increased risk applies to spontaneous as well as iatrogenic preterm delivery.

With regards to spontaneous preterm delivery, a number of preconception interventions may reduce the risk of recurrence: cessation of smoking and recreational drugs, appropriate management of maternal comorbidities, including treatment of genital tract infection, and attainment of a normal body mass index. (1,3,4) In a subsequent pregnancy, treatment of asymptomatic bacteriuria, progesterone administration and cervical cerclage have proven useful in reducing the risk of recurrence in women with a short cervix. (1,3,5,6)

In terms of iatrogenic preterm delivery, a substantial proportion of these cases are related to vascular placental conditions, such as pre-eclampsia and fetal growth restriction. The risk of recurrence of these conditions is higher than in the general population, and can be decreased by low-dose aspirin, calcium supplements, and diet and lifestyle interventions. (2,7,8)

Benefits

Short-term benefits

N/A

Long-term benefits

- Better informed parents (consensus)
- Appropriate preconception or early pregnancy intervention or management (1,3,4)
- Reduced risk of recurrent preterm delivery (1,3–6)
- Reduced risk of recurrent pre-eclampsia and fetal growth restriction (2,7–9)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Mothers and their partners are informed by healthcare professionals on strategies to prevent recurrence of preterm delivery or pregnancy complications, before hospital discharge or at a follow-up visit (see Birth & transfer).	B (High quality)	Patient information sheet
2. Mothers and their partners are supported to help them to cope with uncertainties in outcomes in future pregnancies.	B (High quality)	Parent feedback
For healthcare professionals		
3. A unit guideline on reproductive counselling of women with a previous complicated pregnancy at risk of recurrence, including pathways of integrated antenatal care, is adhered to by all healthcare professionals. (1–8)	A (High quality) B (High quality)	Guideline
4. Training on reproductive counselling of women with a previous complicated pregnancy at risk of recurrence is attended by all responsible healthcare professionals.	B (High quality)	Training documentation
For perinatal and neonatal unit, hospital, and follow-up team		
5. A unit guideline on reproductive counselling of women with a previous complicated pregnancy at risk of recurrence, including pathways of integrated antenatal care is available and regularly updated. (1–8)	A (High quality) B (High quality)	Guideline
6. Communication about maternal health issues that may affect newborn care is maintained.	B (High quality)	Clinical records
7. Training on reproductive counselling of women with a previous complicated pregnancy at risk of recurrence is ensured.	B (High quality)	Training documentation
For health service		
8. A national guideline on reproductive counselling of women with a previous complicated pregnancy at risk of	A (High quality) B (High quality)	Guideline

recurrence, including pathways of integrated antenatal care is available and regularly updated. (1–8)

- | | | |
|--|----------------------|--------------|
| 9. Funding for follow-up care of mothers and for targeted antenatal care in future pregnancies is provided, or included in insurance packages. | B (Moderate quality) | Audit report |
|--|----------------------|--------------|

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, hospital, and follow-up team	
N/A	
For health service	
N/A	

Getting started

Initial steps
For parents and family
Mothers and their partners are informed by healthcare professionals about pregnancy complications and about the availability of targeted care in future pregnancies.
For healthcare professionals
- Attend training on reproductive counselling of women with a previous complicated pregnancy at risk of recurrence. - Establish a structure of communication with other healthcare institutions providing antenatal care.
For perinatal and neonatal unit, hospital, and follow-up team
- A service for providing antenatal care for women at risk of recurrent pregnancy complication is available. - Develop and implement a unit guideline on reproductive counselling. - Develop information material on the follow-up that is available for women at risk of recurrent pregnancy complication. - Support healthcare professionals to participate in trainings on reproductive counselling of women with a previous complicated pregnancy at risk of recurrence. - Provide funding and resources for targeted antenatal care in future pregnancies.
For health service
Develop and implement a national guideline on pathways of care, integrating routine antenatal care for women with a previous complicated pregnancy at risk of recurrence.

Source

1. Iams JD, Berghella V. Care for women with prior preterm birth. *Am J Obstet Gynecol*. 2010 Aug;203(2):89–100.
2. Friedman AM, Cleary KL. Prediction and prevention of ischemic placental disease. *Semin Perinatol*. 2014 Apr;38(3):177–82.
3. Colicchia LC, Simhan HN. Optimizing Subsequent Pregnancy Outcomes for Women with a Prior Preterm Birth. *Am J Perinatol*. 2016 Feb;33(3):267–75.
4. Stang J, Huffman LG. Position of the Academy of Nutrition and Dietetics: Obesity, Reproduction, and Pregnancy Outcomes. *J Acad Nutr Diet*. 2016 Apr;116(4):677–91.
5. Berghella V, Rafael TJ, Szychowski JM, Rust OA, Owen J. Cerclage for short cervix on ultrasonography in women with singleton gestations and previous preterm birth: a meta-analysis. *Obstet Gynecol*. 2011 Mar;117(3):663–71.
6. Norman JE, Marlow N, Messow C-M, Shennan A, Bennett PR, Thornton S, et al. Vaginal progesterone prophylaxis for preterm birth (the OPPTIMUM study): a multicentre, randomised, double-blind trial. *The Lancet*. 2016 May 21;387(10033):2106–16.
7. Costa ML. Preeclampsia: Reflections on How to Counsel About Preventing Recurrence. *J Obstet Gynaecol Can JOGC J Obstet Gynecol Can JOGC*. 2015 Oct;37(10):887–93.
8. Mol BWJ, Roberts CT, Thangaratinam S, Magee LA, de Groot CJM, Hofmeyr GJ. Pre-eclampsia. *The Lancet*. 2016 Mar;387(10022):999–1011.
9. Rolnik DL, Wright D, Poon LC, O’Gorman N, Syngelaki A, de Paco Matallana C, et al. Aspirin versus Placebo in Pregnancies at High Risk for Preterm Preeclampsia. *N Engl J Med*. 2017 Aug 17;377(7):613–22.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

EFCNI, Prefumo F, Johnson MR et al., European Standards of Care for Newborn Health: Reproductive counselling. 2018.

Respiratory outcome

Lehtonen L, Leemhuis AG, Wolke D, Parikka V

Target group

Infants born very preterm or those infants with risk factors (see Follow-up & continuing care), parents, and families

User group

Healthcare professionals (including general practitioners), neonatal units, hospitals, health services, and follow-up teams

Statement of standard

Respiratory health is evaluated as part of a follow-up care programme.

Rationale

Infants born very preterm or infants with risk factors are at increased risk of respiratory morbidity, especially an obstructive airway disease, as compared to full term infants. (1–3) Respiratory symptoms occur most frequently during the first two years (4) but persist through school age and into young adult age. (5–9) At school age, asthma medication is prescribed in up to one third of children born very preterm. (5,8,10) Respiratory disorders, including wheezing during respiratory infections, has been shown to be the most common reason for rehospitalisation in very preterm infants. (11–13)

Those born smallest or most immature or with more severe pulmonary problems during the first hospitalisation (having a diagnosis of bronchopulmonary dysplasia (BPD)) are more likely to have later respiratory and cardiovascular problems. (7,10,12,14–16) There are no published studies assessing the efficacy of routine lung function tests in the follow-up of very preterm infants. However, knowing the increased risks it is important to provide clinical respiratory surveillance for all high-risk infants to identify those who need more detailed tests or intervention. In particular, infants with neonatal bronchopulmonary dysplasia should be followed closely to identify those children needing treatment. In addition, their cardiovascular risk should be kept in mind in adulthood, because of a small increase in the risk of ischaemic heart diseases. (16)

Health promotion is important for this group, in particular, parents and families should avoid passive and active exposure to tobacco smoke and where possible environmental pollution (6,9,11,15–21) and they should protect themselves and the whole family with appropriate vaccinations. A reduced exercise capacity is reported in very low birthweight infants and BPD survivors, but a physical activity programme could improve exercise tolerance, exercise capacity and flexibility in preterm children. (22,23)

Benefits

Short-term benefits

N/A

Long-term benefits

- Improved identification of individuals who require further diagnostic tests or treatment of respiratory conditions (consensus)
- Reduced risk of rehospitalisation (24)
- Reduced school absence (25)

- Reduced number of days of restricted activity (25)
- Reduced emergency room visits (25)
- Improved respiratory health (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents, family and children and adults born preterm		
1. Parents and families are informed about and invited by healthcare professionals to attend follow-up programmes including respiratory assessment. (1,2)	A (High quality) B (High quality)	Patient information sheet
2. Parents and children get recommendations for healthy life style and vaccinations by healthcare professionals. (1,2)	A (High quality)	Patient information sheet
3. Parents receive individual advice regarding day care attendance. (26)	B (Low quality)	Patient information sheet
For healthcare professionals (including general practitioners)		
4. A unit guideline on follow-up including respiratory care is adhered to by all healthcare professionals.	B (High quality)	Guideline
5. Training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking is attended by all responsible healthcare professionals. (12,17,18)	A (High quality) B (High quality)	Training documentation
For neonatal unit, hospital, and follow-up team		
6. A unit guideline on follow-up including respiratory care is available and regularly updated.	B (High quality)	Guideline
7. Symptomatic individuals are referred to appropriate paediatric respiratory services for longer term surveillance.	B (Moderate quality)	Clinical records
8. Training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking is ensured.	B (High quality)	Training documentation

For health service		
9. A national guideline on follow-up including respiratory care is available and regularly updated.	B (High quality)	Guideline
10. RSV immunisation is available for the infants with high risk for hospitalisation. (27–30) Its use should be suited to the local resources as the cost-effectiveness and long-term benefits are still unclear. (31)	A (High quality) A (Low quality)	Audit report, guideline

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
N/A	
For healthcare professionals (including general practitioners)	
N/A	
For neonatal unit, hospital, and follow-up team	
Implement the evidence-based practices about lung protective treatment strategies (see Medical care & clinical practice). (31–33)	A (High quality)
Benchmark and make available respiratory outcomes up to adulthood against similar services. (34)	B (Low quality)
For health service	
Increase awareness of adverse effects of tobacco use and environmental pollution on respiratory health. (18–20)	A (High quality)
Include follow-up information on an electronic healthcare card.	B (Low quality)
Increase adult physicians' awareness about the long-term consequences of preterm birth.	B (Moderate quality)

Getting started

Initial steps
For parents and family
- Parents and families are informed by healthcare professionals about the importance of respiratory health, avoiding exposure to tobacco smoke and promoting a healthy lifestyle. - Parents are informed by healthcare professionals about potential signs of respiratory problems.
For healthcare professionals (including general practitioners)
Attend training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking.
For neonatal unit, hospital, and follow-up team
Develop and implement a unit guideline on follow-up including respiratory care.

- Develop information material about the need for respiratory assessment as part of follow-up programme and of recommendations for healthy life style for parents.
- Support healthcare professionals to participate in training on the appropriate referral and treatment for high-risk infants with respiratory disease and about health promotion including cessation of household smoking.

For health service

- Develop and implement a national guideline on follow-up including respiratory care.
- Develop ways to keep track of high-risk infants including e-health applications.

Source

1. Korvenranta E, Lehtonen L, Peltola M, Häkkinen U, Andersson S, Gissler M, et al. Morbidities and hospital resource use during the first 3 years of life among very preterm infants. *Pediatrics*. 2009 Jul;124(1):128–34.
2. Greenough A. Long-term respiratory consequences of premature birth at less than 32 weeks of gestation. *Early Hum Dev*. 2013 Oct;89 Suppl 2:S25-27.
3. Rusconi F, Gagliardi L. Pregnancy Complications and Wheezing and Asthma in Childhood. *Am J Respir Crit Care Med*. 2018 Mar 1;197(5):580–8.
4. Baraldi E, Filippone M, Trevisanuto D, Zanardo V, Zacchello F. Pulmonary function until two years of life in infants with bronchopulmonary dysplasia. *Am J Respir Crit Care Med*. 1997 Jan;155(1):149–55.
5. Lum S, Kirkby J, Welsh L, Marlow N, Hennessy E, Stocks J. Nature and severity of lung function abnormalities in extremely pre-term children at 11 years of age. *Eur Respir J*. 2011 May;37(5):1199–207.
6. Doyle LW, Adams AM, Robertson C, Ranganathan S, Davis NM, Lee KJ, et al. Increasing airway obstruction from 8 to 18 years in extremely preterm/low-birthweight survivors born in the surfactant era. *Thorax*. 2017;72(8):712–9.
7. Hirata K, Nishihara M, Kimura T, Shiraishi J, Hirano S, Kitajima H, et al. Longitudinal impairment of lung function in school-age children with extremely low birth weights. *Pediatr Pulmonol*. 2017 Jun;52(6):779–86.
8. Simpson SJ, Logie KM, O'Dea CA, Banton GL, Murray C, Wilson AC, et al. Altered lung structure and function in mid-childhood survivors of very preterm birth. *Thorax*. 2017;72(8):702–11.
9. Moschino L, Stocchero M, Filippone M, Carraro S, Baraldi E. Longitudinal Assessment of Lung Function in Survivors of Bronchopulmonary Dysplasia from Birth to Adulthood. The Padova BPD Study. *Am J Respir Crit Care Med*. 2018 Jul;198(1):134–7.
10. Broström EB, Thunqvist P, Adenfelt G, Borling E, Katz-Salamon M. Obstructive lung disease in children with mild to severe BPD. *Respir Med*. 2010 Mar;104(3):362–70.
11. Gray D, Woodward LJ, Spencer C, Inder TE, Austin NC. Health service utilisation of a regional cohort of very preterm infants over the first 2 years of life. *J Paediatr Child Health*. 2006 Jun;42(6):377–83.
12. Hennessy EM, Bracewell MA, Wood N, Wolke D, Costeloe K, Gibson A, et al. Respiratory health in pre-school and school age children following extremely preterm birth. *Arch Dis Child*. 2008 Dec;93(12):1037–43.
13. Ralser E, Mueller W, Haberland C, Fink FM, Gutenberger KH, Strobl R, et al. Rehospitalization in the first 2 years of life in children born preterm. *Acta Paediatr Oslo Nor* 1992. 2012 Jan;101(1):e1-5.

14. Doyle LW, Faber B, Callanan C, Freezer N, Ford GW, Davis NM. Bronchopulmonary dysplasia in very low birth weight subjects and lung function in late adolescence. *Pediatrics*. 2006 Jul;118(1):108–13.
15. Vom Hove M, Prenzel F, Uhlig HH, Robel-Tillig E. Pulmonary outcome in former preterm, very low birth weight children with bronchopulmonary dysplasia: a case-control follow-up at school age. *J Pediatr*. 2014 Jan;164(1):40-45.e4.
16. Crump C, Howell EA, Stroustrup A, McLaughlin MA, Sundquist J, Sundquist K. Association of Preterm Birth With Risk of Ischemic Heart Disease in Adulthood. *JAMA Pediatr*. 2019 Aug 1;173(8):736–43.
17. Doyle LW, Olinsky A, Faber B, Callanan C. Adverse Effects of Smoking on Respiratory Function in Young Adults Born Weighing Less Than 1000 Grams. *Pediatrics*. 2003 Sep 1;112(3):565–9.
18. Svanes C. Parental smoking in childhood and adult obstructive lung disease: results from the European Community Respiratory Health Survey. *Thorax*. 2004 Apr 1;59(4):295–302.
19. Moshhammer H, Hoek G, Luttmann-Gibson H, Neuberger MA, Antova T, Gehring U, et al. Parental smoking and lung function in children: an international study. *Am J Respir Crit Care Med*. 2006 Jun 1;173(11):1255–63.
20. Jones LL, Hashim A, McKeever T, Cook DG, Britton J, Leonardi-Bee J. Parental and household smoking and the increased risk of bronchitis, bronchiolitis and other lower respiratory infections in infancy: systematic review and meta-analysis. *Respir Res*. 2011 Jan 10;12:5.
21. Shen Y, Wu Y, Chen G, Van Grinsven HJM, Wang X, Gu B, et al. Non-linear increase of respiratory diseases and their costs under severe air pollution. *Environ Pollut Barking Essex 1987*. 2017 May;224:631–7.
22. Yang J, Epton MJ, Harris SL, Horwood J, Kingsford RA, Troughton R, et al. Reduced Exercise Capacity in Adults Born at Very Low Birth Weight: A Population-based Cohort Study. *Am J Respir Crit Care Med*. 2022 Jan 1;205(1):88–98.
23. Mestre NM, Papaleo A, Hidalgo VM, Caty G, Reyhler G. Physical Activity Program Improves Functional Exercise Capacity and Flexibility in Extremely Preterm Children With Bronchopulmonary Dysplasia Aged 4–6 Years: A Randomized Controlled Trial. *Arch Bronconeumol Engl Ed*. 636792192000000000;54(12):607–13.
24. Razi CH, Cörüt N, Andiran N. Budesonide reduces hospital admission rates in preschool children with acute wheezing. *Pediatr Pulmonol*. 2017 Jun;52(6):720–8.
25. Wolf FM, Guevara JP, Grum CM, Clark NM, Cates CJ. Educational interventions for asthma in children. *Cochrane Database Syst Rev*. 2003;(1):CD000326.
26. Duijts L, van Meel ER, Moschino L, Baraldi E, Barnhoorn M, Bramer WM, et al. European Respiratory Society guideline on long-term management of children with bronchopulmonary dysplasia. *Eur Respir J*. 2020 Jan;55(1):1900788.
27. Palivizumab, a humanized respiratory syncytial virus monoclonal antibody, reduces hospitalization from respiratory syncytial virus infection in high-risk infants. The IMPact-RSV Study Group. *Pediatrics*. 1998 Sep;102(3 Pt 1):531–7.
28. Homaira N, Rawlinson W, Snelling TL, Jaffe A. Effectiveness of Palivizumab in Preventing RSV Hospitalization in High Risk Children: A Real-World Perspective. *Int J Pediatr*. 2014;2014:571609.
29. Andabaka T, Nickerson JW, Rojas-Reyes MX, Rueda JD, Vrca VB, Barsic B. Monoclonal antibody for reducing the risk of respiratory syncytial virus infection in children. *Cochrane Database Syst Rev [Internet]*. 2013 [cited 2018 Nov 12];(4). Available from: <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006602.pub4/abstract>
30. Griffin MP, Yuan Y, Takas T, Domachowske JB, Madhi SA, Manzoni P, et al. Single-Dose Nirsevimab for Prevention of RSV in Preterm Infants. *N Engl J Med*. 2020 Jul 30;383(5):415–25.



31. Scheltema NM, Nibbelke EE, Pouw J, Blanken MO, Rovers MM, Naaktgeboren CA, et al. Respiratory syncytial virus prevention and asthma in healthy preterm infants: a randomised controlled trial. *Lancet Respir Med*. 2018;6(4):257–64.
32. Lapcharoensap W, Gage SC, Kan P, Profit J, Shaw GM, Gould JB, et al. Hospital variation and risk factors for bronchopulmonary dysplasia in a population-based cohort. *JAMA Pediatr*. 2015 Feb;169(2):e143676.
33. Lee SK, Aziz K, Singhal N, Cronin CM. The Evidence-based Practice for Improving Quality method has greater impact on improvement of outcomes than dissemination of practice change guidelines and quality improvement training in neonatal intensive care units. *Paediatr Child Health*. 2015 Feb;20(1):e1-9.
34. National Neonatal Audit Programme (NNAP) | RCPCH [Internet]. [cited 2018 May 25]. Available from: <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/national-neonatal-audit-programme-nnap>

Second edition, September 2022

Lifecycle

3 years/next revision: 2025

Recommended citation

EFCNI, Lehtonen L, Leemhuis AG et al., European Standards of Care for Newborn Health: Respiratory outcome. 2022.

Transition from hospital to home

Hüning BM, Härtel C, Wolke D, Leemhuis AG

Target group

Infants born very preterm or those infants with risk factors (see preamble of Follow-up & continuing care), parents, and families

User group

Healthcare professionals, neonatal units, hospitals, follow-up teams, and health services

Statement of standard

Families receive a comprehensive discharge management plan to facilitate transition from the hospital to home.

Rationale

The goal is to support the family of high-risk infants following discharge from hospital, to ensure continuity of care, full vaccination, and to avoid unnecessary rehospitalisation.

Early discharge of very preterm infants is possible without adverse effects if decided on the basis of the infant's physical maturation and competency (e.g. feeding, temperature control, respiratory stability), rather than a certain body weight or gestational age. (1–3)

To minimise their high vulnerability to infections, very preterm infants should receive full-dose vaccinations at their chronological age as opposed to their corrected age, even if they are still hospitalised. In addition, family members and other close contacts of the preterm infant should be up-to-date with their vaccinations (preventive concept of “cocooning”; see standard Immunisation of preterm infants). (4–6)

Discharge management (7) is complex and requires careful timing and planning, and should be commenced as early as possible by a multidisciplinary team to ensure continuity of care. Evaluation of discharge readiness has to address the infant as well as the family and community/healthcare system that ensure continuing care. Parental education and psychosocial support are key elements of continuous discharge management. (3) Successful preparation for discharge improves outcomes of very preterm infants in the transition from hospital to home (8), reduces the length of hospital stay (2,9,10) healthcare usage and costs. (11)

Benefits

Short-term benefits

- Reduced length of hospital stay and costs (2,9,10)
- Reduced risk of hospital-acquired mortality and morbidity (2,3)

Long-term benefits

- Seamless care (12)
- Minimised separation of parents and infant (3)
- Continued family support (3)
- Reduced healthcare visits after discharge (2,9,10)
- Reduced infant mortality and morbidity (13,14)
- Reduced rate of readmissions (9)
- Increased rate of complete vaccination (consensus)

- Improved parental competence and confidence (12,15)
- Reduced stress for parents and family (8)
- Improved parental mental health and resilience (10)
- Improved interdisciplinary cooperation and cross-sectoral collaboration for the benefit of the families (12)
- Reduced healthcare costs and costs for the family (8)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and families		
1. Parents are informed and assisted by healthcare professionals in order to participate in care procedures and decision-making from admission to discharge management. (1,10,16)	A (High quality) B (High quality)	Parent feedback, patient information sheet
2. Parents are informed by healthcare professionals about: (1,13,17–19) • symptoms and signs of illness of their infant and how to respond • the importance of vaccination of infants and their household contacts • breastfeeding • safe sleeping environment • car seat safety • no smoking environment • follow-up visits for ongoing medical problems, growth, and neurodevelopment • post-discharge positive parenting intervention programmes	A (High quality) B (High quality)	Parent feedback, patient information sheet
3. Parents receive ongoing psychosocial support that is adapted to their individual needs and resources. (3,20,21)	A (High quality)	Guideline, parent feedback
4. Discharge planning includes training and resuscitation for high-risk infants. (3,20,21)	A (High quality)	Training documentation
For healthcare professionals		
5. A unit guideline on the management of the transition from hospital to home is adhered to by all healthcare professionals.	B (High quality)	Guideline
6. Training on the assessment of discharge readiness using a standard guideline as well as on current national vaccination guidelines, including safety	A (High quality) B (High quality)	Guideline, training documentation

and efficacy data of vaccines related to preterm infants is attended by all responsible healthcare professionals. (1,7,22–24)

- | | | |
|--|----------------------|------------------|
| 7. Healthcare professionals communicate with the primary care physician and provide a written discharge summary. (3) | B (Moderate quality) | Clinical records |
|--|----------------------|------------------|

For neonatal unit, hospital, and follow-up team

- | | | |
|---|--|-----------------------------------|
| 8. A unit guideline on the management of the transition from hospital to home is available and regularly updated. | B (High quality) | Guideline |
| 9. A multidisciplinary meeting is arranged for each high-risk infant prior to discharge. (3,9) | A (Moderate quality)
B (Moderate quality) | Guideline |
| 10. Discharge planning is continuously assessed from admission. (9,24) | A (Moderate quality) | Clinical records, guideline |
| 11. Regular meetings to discuss parental participation and competencies, family, and social issues are organised. (3,9) | A (Moderate quality)
B (Moderate quality) | Clinical records, guideline |
| 12. Training on the assessment of discharge readiness using a standard guideline as well as on current national vaccination guidelines, including safety and efficacy data of vaccines related to preterm infants is ensured. | B (High quality) | Guideline, training documentation |
| 13. Rooms and equipment for counselling/training of parents are available. | B (High quality) | Audit report |

For health service

- | | | |
|--|------------------|-----------|
| 14. A national guideline on the management of the transition from hospital to home is available and regularly updated. | B (High quality) | Guideline |
|--|------------------|-----------|

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
Offer a family-centred care programme with follow-up home visits (see Follow-up & continuing care). (1–3,9,25)	A (High quality) B (Moderate quality)
For healthcare professionals	
Offer special education and skills to follow-up team, e.g. case management, communication, social work. (9)	B (High quality)
For neonatal unit, hospital, and follow-up team	
Provide support services for siblings. (3,24)	B (Low quality)
Enable residence facilities for families. (12,26,27)	B (Low quality)
For health service	
Provide framework enabling parents to be with their infants (e.g. parental leave, financial support for travelling, accommodation). (28)	B (Low quality)

Getting started

Initial steps

For parents and family

- Parents and family are informed by healthcare professionals about specific health requirements of their infant (including vaccination, nutrition, safe sleeping, car seats and complex medical needs e.g. gavage feeding, dietary supplements and respiratory care).
- Participation of parents is supported (repetitive training in care procedures and if necessary registration with a physician).

For healthcare professionals

- Attend training on the assessment of discharge readiness using a standard guideline as well as on current national vaccination guidelines, including safety and efficacy data of vaccines related to preterm infants.
- Establish a structure of communication with primary care physician, community/healthcare services and follow-up services.
- Identify a coordinator for discharge management (e.g. case manager, family nurse, etc.).

For neonatal unit, hospital, and follow-up team

- Develop and implement a unit guideline for the assessment of discharge readiness and pre-discharge screening.
- Develop and implement a unit guideline on the management of the transition from hospital to home.
- Develop information material on different health topics relevant for discharge of preterm born infants for parents.
- Provide information material in families' preferred language and medical interpreters for discharge management meeting if possible. (29)
- Institute regular meetings with physicians and coordinating staff and additionally a discharge meeting with parents.
- Support healthcare professionals to participate in training on the assessment of discharge readiness using a standard guideline as well as on current national

vaccination guidelines, including safety and efficacy data of vaccines related to preterm infants.

- Provide at least one coordinating professional, room, and equipment for discharge management.

For health service

- Develop and implement a national guideline on discharge management.
- Define quality markers for discharge care.

Description

Core elements of discharge management are:

- Infant: completion of primary care (including vaccination) and pre-discharge screening in the hospital, organisation of medical care/technical assistance for unresolved medical problems.
- Family: parental education and participation in care procedures and discharge planning, identification of family stressors and risk factors as well as family resources, up-to-date vaccinations including influenza and pertussis boosters of family members (household contacts) and the mother during pregnancy (see standard Immunisation of preterm infants). (6)
- Community/healthcare system: development of a comprehensive home care plan, assessment of social and financial needs, parental mental health issues and (30,31), involvement of support services, communication with primary care providers and follow-up arrangements to monitor growth and development

Example of a checklist used for discharge management

1. Discharge readiness

a. INFANT

- Oral feeding (breast or bottle) and appropriate growth
- Maintenance of body temperature in ambient temperature of 22-24°C
- Respiratory stability without episodes of apnoea and bradycardia (5-8 days following discontinuation of caffeine treatment) (32)
- Discharge is possible and safe with gavage feeding (33) provided that home care and monitoring is organised and parents trained

b. PARENTS

- Consistent involvement in care procedures
- Competency to provide home care (individual teaching plan – knowledge and skills-completed) (8,24)
- Counselling (vaccination, safe sleeping environment, household smoking, safe usage of car seat, follow-up visits) complete (3)
- Home environment prepared (8)
- On-going family psychosocial support programme (if available)

c. COMMUNITY/HEALTHCARE SYSTEM

- Primary care and medical special care physicians informed (1,24)
- Appointments for follow-up visits arranged and confirmed
- Written summary of hospital course, recommendations and home care plan (3,24)
- Additional care givers identified (grandparents, community services)
- Home care plan in place (special medical equipment, nutrition, medication, home care nursing, follow-up visits confirmed etc.) (1,3)
- Assistance for financial and community support in place

2. Pre-discharge screening and care procedures

- Completed screening for metabolic/genetic disorders, anaemia and nutritional deficiencies. (3,34,35)
- Routine screening for retinopathy of prematurity (36)
- Hearing screening with auditory brain stem response (37)
- Brain imaging (ultra sound and/or MRI, if available) in at risk infants (38)
- Start full vaccination following chronologic age, consider RSV prophylaxis and influenza vaccination if applicable

3. Parental competencies

- Basic care procedures (washing, nappy change, etc.)
- Feeding techniques
- Medication administration
- Safe sleeping environment (13,14)
- Safe car seat usage (18)
- Special care procedures (e.g. gavage feeding, respiratory treatment, usage of home monitor, suctioning, oxygen) (3,33)
- Cardiopulmonary resuscitation

Vaccinations

Vaccination schedules are a central part of discharge planning. Due to the great complexity of the subject, an entire standard was designated to the topic, which replaces the previous recommendations of the first version of this standard (see Immunisation of preterm infants). (6)

Source

1. Merritt TA, Pillers D, Prows SL. Early NICU discharge of very low birth weight infants: a critical review and analysis. *Semin Neonatol* SN. 2003 Apr;8(2):95–115.
2. Brooten D, Kumar S, Brown LP, Butts P, Finkler SA, Bakewell-Sachs S, et al. A randomized clinical trial of early hospital discharge and home follow-up of very-low-birth-weight infants. *NLN Publ.* 1987 Aug;(21–2194):95–106.
3. Committee on Fetus and Newborn. Hospital Discharge of the High-Risk Neonate. *PEDIATRICS*. 2008 Nov 1;122(5):1119–26.
4. Bonhoeffer J, Siegrist CA, Heath PT. Immunisation of premature infants. *Arch Dis Child*. 2006 Nov;91(11):929–35.
5. de Greeff SC, de Melker HE, Westerhof A, Schellekens JFP, Mooi FR, van Boven M. Estimation of household transmission rates of pertussis and the effect of cocooning vaccination strategies on infant pertussis. *Epidemiol Camb Mass*. 2012 Nov;23(6):852–60.
6. Härtel C, Wolke D, Leemhuis A, Mader S, Fortmann I, Goettler D, et al. Immunisation of preterm infants. *EFCNI*; 2022.
7. Denizot S, Fleury J, Caillaux G, Rouger V, Rozé JC, Gras-Le Guen C. Hospital initiation of a vaccinal schedule improves the long-term vaccinal coverage of ex-preterm children. *Vaccine*. 2011 Jan 10;29(3):382–6.

8. Smith VC, Hwang SS, Dukhovny D, Young S, Pursley DM. Neonatal intensive care unit discharge preparation, family readiness and infant outcomes: connecting the dots. *J Perinatol*. 2013 Jun;33(6):415–21.
9. Hüning BM, Reimann M, Beerenberg U, Stein A, Schmidt A, Felderhoff-Müser U. Establishment of a family-centred care programme with follow-up home visits: implications for clinical care and economic characteristics. *Klin Padiatr*. 2012 Nov;224(7):431–6.
10. Melnyk BM, Feinstein NF, Alpert-Gillis L, Fairbanks E, Crean HF, Sinkin RA, et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics*. 2006 Nov;118(5):e1414-1427.
11. Ingram JC, Powell JE, Blair PS, Pontin D, Redshaw M, Manns S, et al. Does family-centred neonatal discharge planning reduce healthcare usage? A before and after study in South West England. *BMJ Open*. 2016 Mar;6(3):e010752.
12. Broedsgaard A, Wagner L. How to facilitate parents and their premature infant for the transition home. *Int Nurs Rev*. 2005 Sep;52(3):196–203.
13. Task Force on Sudden Infant Death Syndrome, Moon RY. SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment. *Pediatrics*. 2011 Nov;128(5):1030–9.
14. Goodstein MH, Stewart DL, Keels EL, Moon RY, COMMITTEE ON FETUS AND NEWBORN, TASK FORCE ON SUDDEN INFANT DEATH SYNDROME. Transition to a Safe Home Sleep Environment for the NICU Patient. *Pediatrics*. 2021 Jul;148(1):e2021052046.
15. Griffin T, Abraham M. Transition to home from the newborn intensive care unit: applying the principles of family-centered care to the discharge process. *J Perinat Neonatal Nurs*. 2006 Sep;20(3):243–9; quiz 250–1.
16. Raines DA, Brustad J. Parent's confidence as a caregiver. *Adv Neonatal Care Off J Natl Assoc Neonatal Nurses*. 2012 Jun;12(3):183–8.
17. Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database Syst Rev*. 2015 Nov 24;(11):CD005495.
18. Bull MJ, Engle WA. Safe Transportation of Preterm and Low Birth Weight Infants at Hospital Discharge. *Pediatrics*. 2009 May 1;123(5):1424–9.
19. Pilley E, McGuire W. Pre-discharge "car seat challenge" for preventing morbidity and mortality in preterm infants. *Cochrane Database Syst Rev*. 2006 Jan 25;(1):CD005386.
20. Kun S, Warburton D. Telephone assessment of parents' knowledge of home-care treatments and readmission outcomes for high-risk infants and toddlers. *Am J Dis Child* 1960. 1987 Aug;141(8):888–92.
21. van Wassenaeer-Leemhuis AG, Jeukens-Visser M, van Hus JWP, Meijssen D, Wolf MJ, Kok JH, et al. Rethinking preventive post-discharge intervention programmes for very preterm infants and their parents. *Dev Med Child Neurol*. 2016 Mar;58 Suppl 4:67–73.
22. Graumlich JF, Grimmer-Somers K, Aldag JC. Discharge planning scale: community physicians' perspective. *J Hosp Med*. 2008 Dec;3(6):455–64.
23. American Academy of Pediatrics. Immunization in special circumstances. In: Kimberlin D, Brady M, Jackson M, Long S, editors. *Red Book: 2012 Report of the Committee on Infectious Diseases*. Vol II. Elk Grove: American Academy of Pediatrics; 2015. p. 68.
24. Smith VC, Dukhovny D, Zupancic JAF, Gates HB, Pursley DM. Neonatal Intensive Care Unit Discharge Preparedness: Primary Care Implications. *Clin Padiatr (Phila)*. 2012 May 1;51(5):454–61.



25. Koldewijn K, van Wassenae A, Wolf MJ, Meijssen D, Houtzager B, Beelen A, et al. A neurobehavioral intervention and assessment program in very low birth weight infants: outcome at 24 months. *J Pediatr*. 2010 Mar;156(3):359–65.
26. Toivonen M, Lehtonen L, Löyttyniemi E, Axelin A. Effects of single-family rooms on nurse-parent and nurse-infant interaction in neonatal intensive care unit. *Early Hum Dev*. 2017 Apr;106–107:59–62.
27. Shahheidari M, Homer C. Impact of the design of neonatal intensive care units on neonates, staff, and families: a systematic literature review. *J Perinat Neonatal Nurs*. 2012 Sep;26(3):260–6; quiz 267–8.
28. Maree C, Downes F. Trends in Family-Centered Care in Neonatal Intensive Care. *J Perinat Neonatal Nurs*. 2016 Sep;30(3):265–9.
29. Obregon E, Martin CR, Frantz IJ, Patel P, Smith VC. Neonatal Intensive Care Unit discharge preparedness among families with limited english proficiency. *J Perinatol Off J Calif Perinat Assoc*. 2019 Jan;39(1):135–42.
30. Miles MS, Holditch-Davis D, Schwartz TA, Scher M. Depressive symptoms in mothers of prematurely born infants. *J Dev Behav Pediatr JDBP*. 2007 Feb;28(1):36–44.
31. Rogers CE, Kidokoro H, Wallendorf M, Inder TE. Identifying mothers of very preterm infants at-risk for postpartum depression and anxiety before discharge. *J Perinatol Off J Calif Perinat Assoc*. 2013 Mar;33(3):171–6.
32. Eichenwald E. Apnea of Prematurity. In: Brodsky D, editor. *Primary Care of the Premature Infant*. Philadelphia: Saunders Elsevier; 2008. p. 19.
33. Collins CT, Makrides M, McPhee AJ. Early discharge with home support of gavage feeding for stable preterm infants who have not established full oral feeds. *Cochrane Database Syst Rev*. 2003;(4):CD003743.
34. Kaye CI. Newborn Screening Fact Sheets. *Pediatrics*. 2006 Sep 1;118(3):e934–63.
35. Baker RD, Greer FR, Committee on Nutrition American Academy of Pediatrics. Diagnosis and prevention of iron deficiency and iron-deficiency anemia in infants and young children (0-3 years of age). *Pediatrics*. 2010 Nov;126(5):1040–50.
36. Fierson WM, AMERICAN ACADEMY OF PEDIATRICS Section on Ophthalmology, AMERICAN ACADEMY OF OPHTHALMOLOGY, AMERICAN ASSOCIATION FOR PEDIATRIC OPHTHALMOLOGY AND STRABISMUS, AMERICAN ASSOCIATION OF CERTIFIED ORTHOPTISTS. Screening Examination of Premature Infants for Retinopathy of Prematurity. *Pediatrics*. 2018 Dec;142(6):e20183061.
37. American Academy of Pediatrics, Joint Committee on Infant Hearing. Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*. 2007 Oct;120(4):898–921.
38. Inder TE, de Vries LS, Ferriero DM, Grant PE, Ment LR, Miller SP, et al. Neuroimaging of the Preterm Brain: Review and Recommendations. *J Pediatr*. 2021 Oct;237:276–287.e4.

Second edition, September 2022

Lifecycle

3 years/next revision: 2025

Recommended citation

EFCNI, Hüning BM, Härtel C et al., European Standards of Care for Newborn Health: Transition from hospital to home. 2022.