Follow-up & continuing care
Topic Expert Group

Follow-up & continuing care

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**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, behavioral and motor development are addressed in all infants, and interventions, such as family-centered 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 behavior 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.
Sources:


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


Assessment of visual function

Ortibus E, van Wassenaer-Leemhuis A, Wolke D, Termote J, Cassiman C, Geldof C

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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 payed 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**

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are 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)</td>
<td>A (High quality) B (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>2. Parents receive standardised feedback about the results of their child’s visual health screening in a language that is accessible to them.</td>
<td>B (High quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>3. Parents are informed about the need for early intervention and support in case of visual impairments.</td>
<td>B (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>4. Parents are asked for permission to allow their child’s medical and educational information to be used for outcome measures.</td>
<td>B (Low quality)</td>
<td>Parent consent, patient information sheet</td>
</tr>
<tr>
<td>5. Parents are asked to consent to share the results of their child’s visual screening tests with education services.</td>
<td>B (Moderate quality)</td>
<td>Parent consent</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. A guideline on follow-up programme including visual assessment is adhered to by all healthcare professionals.</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>7. Training on standardised visual assessment in high-risk infants in which</td>
<td>A (High quality) B (High quality)</td>
<td>Training documentation</td>
</tr>
</tbody>
</table>
gestational age, ROP status, and brain damage are taken into account is attended by all responsible healthcare professionals. (1,2,11–13)

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 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)

10. Children with clinical suspicion for visual perception dysfunctions are assessed at 5 years of age onwards. (15)

For neonatal unit, hospital and follow-up team
11. A guideline on follow-up programme including visual assessment is available and regularly updated.  

12. A follow-up programme after discharge including visual assessment is funded and supported.

13. Training on standardised visual assessment in high-risk infants is ensured.

For health service
14. A national guideline on follow-up programme including visual assessment is available and regularly updated.

15. A follow-up service including visual assessment is specified, funded and monitored.
Where to go – further development of care

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For parents and family</strong></td>
<td></td>
</tr>
<tr>
<td>• Offer visual follow-up until adult age. (16)</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>• Families are supported by case manager in order to ensure follow-up programme including visual assessments.</td>
<td>B (High quality)</td>
</tr>
<tr>
<td><strong>For healthcare professionals</strong></td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td><strong>For neonatal unit and follow-up team</strong></td>
<td></td>
</tr>
<tr>
<td>• Establish an integrated electronic system with follow-up provider to schedule follow-up visits.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td><strong>For hospital and follow-up team</strong></td>
<td></td>
</tr>
<tr>
<td>• Establish multidisciplinary teams, including ophthalmologist/neuropsychologist specialised in visual perception, to evaluate high-risk children. (2)</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td><strong>For health service</strong></td>
<td></td>
</tr>
<tr>
<td>• Support the development of reliable and valid instruments to assess cerebral visual deficits with country specific norms and facilitate differential diagnosis. (11,15)</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>• Develop a national network for benchmarking of follow-up quality.</td>
<td>B (High quality)</td>
</tr>
</tbody>
</table>

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


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citation
Cognitive development

Wolke D, van Wassenaer-Leemhuis AG

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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**

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

<table>
<thead>
<tr>
<th>Further development</th>
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</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td></td>
</tr>
<tr>
<td>• Cognitive follow-up at transition to secondary/high-school age is offered.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>• Parents are supported by a case manager. (26) (see TEG Follow-up &amp; continuing care)</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>• Incentives to attend follow-up programmes are provided. (2,19,27)</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td>N/A</td>
</tr>
<tr>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>For neonatal unit and follow-up team</td>
<td></td>
</tr>
<tr>
<td>• Establish an integrated electronic system with cognitive follow-up provider to schedule follow-up visits.</td>
<td>B (Low quality)</td>
</tr>
</tbody>
</table>
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


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citation
EFCNI, Wolke D, van Wassenaer-Leemhuis AG, European Standards of Care for Newborn Health: Cognitive development; 2018.
Communication, speech, and language

Sansavini A, Bosch L, Wolke D, van Wassenaer-Leemhuis A

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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 ethnic 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**

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including speech and language assessments.</td>
<td>B (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>2. Parents receive standardised feedback in language that is accessible to them.</td>
<td>B (High quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>3. Parents are encouraged to communicate with their infant and expose them to language during family-centered care. (4,29) (see TEG Infant- &amp; family-centred developmental care; see TEG Follow-up &amp; continuing care)</td>
<td>B (High quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>4. A guideline on standardised follow-up programme including speech and language assessments is adhered to by all healthcare professionals.</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>5. Country specific test norms are applied when interpreting the results of screening tests. (30)</td>
<td>A (High quality)</td>
<td>Training documentation</td>
</tr>
</tbody>
</table>
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

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**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

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**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**

<table>
<thead>
<tr>
<th>Further development</th>
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</tr>
<tr>
<td>• Parents are supported by a case manager. (see TEG Follow-up &amp; continuing care).</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>• Parents are provided with incentives to attend follow-up for those who are socially disadvantaged.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>• Families receive support in communication and language strategies.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td><strong>For healthcare professionals</strong></td>
<td>N/A</td>
</tr>
<tr>
<td><strong>For neonatal unit, hospital, and follow-up team</strong></td>
<td></td>
</tr>
<tr>
<td>• Establish an integrated electronic system with communication, speech, and language follow-up provider to schedule follow-up visits.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>• Provide a dedicated assessment facility.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>• Support feeding, functioning or communication by physiotherapists and speech therapists.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td><strong>For health service</strong></td>
<td></td>
</tr>
<tr>
<td>• Develop a national network for benchmarking of follow-up quality.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>• Provide common observation and clinical tools for identifying early indexes of risk of language delay in preterm children.</td>
<td>B (Moderate quality)</td>
</tr>
</tbody>
</table>

**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


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, van Wassenaer-Leemhuis, Wolke D

**Target group**
Infants born very preterm or those infants with risk factors (see preamble TEG 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**

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are 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)</td>
<td>A (Low quality) B (High quality)</td>
<td>Clinical records, patient information sheet</td>
</tr>
<tr>
<td>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)</td>
<td>A (Low quality) B (High quality)</td>
<td>Audit report, parent feedback, patient information sheet</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>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.</td>
<td>B (High quality)</td>
<td>Training documentation</td>
</tr>
<tr>
<td>5. Case managers work with parents to facilitate parental engagement and decision making during follow-up care. (5,12,22,28,33–36)</td>
<td>A (Low quality) B (High quality)</td>
<td>Guideline, parent feedback</td>
</tr>
<tr>
<td>6. Information exchange between all involved healthcare professionals and parents is documented and monitored. (3,10,11,14)</td>
<td>B (Moderate quality)</td>
<td>Clinical records</td>
</tr>
</tbody>
</table>
7. Contacts as part of the local follow-up programme are planned and coordinated, and meet the specific 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)

For hospital and follow-up team
9. Training on specific needs of high-risk infants in general, and follow-up management is ensured.

10. Appropriate resources and facilities for follow-up programme are provided to optimise coordination of healthcare professional input for family.

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.

Where to go – further development of care

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td>N/A</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td>N/A</td>
</tr>
<tr>
<td>For neonatal unit and follow-up team</td>
<td></td>
</tr>
<tr>
<td>• Develop the accessibility of follow-up services, using e-health technology to support parents and health professionals. (35,36)</td>
<td>A (Low quality)</td>
</tr>
<tr>
<td>• Develop the most effective ways of communication between multidisciplinary team members and parents.</td>
<td>B (Moderate quality)</td>
</tr>
<tr>
<td>For hospital and follow-up team</td>
<td>N/A</td>
</tr>
<tr>
<td>For health service</td>
<td></td>
</tr>
<tr>
<td>• Improve digital communication, integrating patient files and databases to facilitate timely handover, and ongoing care. (15)</td>
<td>A (Low quality)</td>
</tr>
<tr>
<td></td>
<td>B (Moderate quality)</td>
</tr>
</tbody>
</table>
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


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, van Wassenaer-Leemhuis A, Wolke D

**Target group**
Children and adults born very preterm or those with risk factors (see preamble TEG 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

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family as well as children and adults born preterm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality) B (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality) B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>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)</td>
<td>A (Moderate quality) B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>4. Physical activity, diet and other aspects of healthy lifestyle are assessed and adequate support to promote healthy lifestyle as necessary is provided. (13)</td>
<td>A (Moderate quality) B (High quality)</td>
<td>Guideline</td>
</tr>
</tbody>
</table>
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 and adults born preterm is available and regularly updated. B (High quality) Guideline

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) 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

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td>N/A</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td>N/A</td>
</tr>
<tr>
<td>For neonatal unit, hospital and follow-up team</td>
<td>N/A</td>
</tr>
<tr>
<td>For health service</td>
<td>N/A</td>
</tr>
<tr>
<td>• Develop evidence-base for preventive strategies.</td>
<td>A (Low quality)</td>
</tr>
</tbody>
</table>
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


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citation
Hearing screening

Oudesluys-Murphy AM, van Wassenaer-Leemhuis A, Wolke D, van Straaten HLM

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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**

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For parents and family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are informed about universal neonatal hearing screening, and invited and encouraged by healthcare professionals to participate. (4,5)</td>
<td>A (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td></td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>2. Parents receive standardised feedback about the results of their child’s hearing screening in language that is accessible to them.</td>
<td>B (Moderate quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality)</td>
<td>Clinical records, guideline, patient information sheet</td>
</tr>
<tr>
<td></td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality)</td>
<td>Guideline, patient information sheet</td>
</tr>
<tr>
<td></td>
<td>B (High quality)</td>
<td></td>
</tr>
</tbody>
</table>
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

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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) Guideline

B (High quality)

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) Training documentation

B (High quality)

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) Guideline

B (High quality)
### For neonatal unit, hospital and follow-up team

<table>
<thead>
<tr>
<th></th>
<th>A guideline on hearing screening and referral for further interventions where necessary is available and regularly updated.</th>
<th>B (High quality)</th>
<th>Guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.</td>
<td>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)</td>
<td>A (High quality) B (High quality)</td>
<td>Audit report</td>
</tr>
<tr>
<td>13.</td>
<td>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.</td>
<td>B (High quality)</td>
<td>Training documentation</td>
</tr>
<tr>
<td>14.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### For health service

<table>
<thead>
<tr>
<th></th>
<th>A national guideline on universal neonatal hearing screening and referral for further interventions where necessary is available and regularly updated.</th>
<th>B (High quality)</th>
<th>Guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.</td>
<td>16. A national legal framework and funding is provided for hearing screening, diagnostic investigations, auditory habilitation, education, care, and follow-up. (3–5)</td>
<td>A (High quality) B (Moderate quality)</td>
<td>Legal framework</td>
</tr>
<tr>
<td>16.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

### Where to go – further development of care

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For parents and family</strong></td>
<td></td>
</tr>
<tr>
<td>• 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.</td>
<td>B (High quality)</td>
</tr>
<tr>
<td>• Provide funding to allow parents who are socially disadvantaged to participate in the follow-up hearing evaluations and interventions.</td>
<td>B (High quality)</td>
</tr>
</tbody>
</table>

| **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


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citation
Meeting special needs at school

Jaekel J, Johnson S, Wolke D, van Wassenaer-Leemhuis A

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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 TEG 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**

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality) B (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>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)</td>
<td>B (Moderate quality)</td>
<td>Parent feedback, patient information sheet</td>
</tr>
<tr>
<td>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)</td>
<td>A (Moderate quality) B (Moderate quality)</td>
<td>Guideline, parent feedback</td>
</tr>
<tr>
<td>4. Parents are asked for consent to share the results of their child’s screening</td>
<td>B (High quality) C (High quality)</td>
<td>Parent consent</td>
</tr>
</tbody>
</table>
and/or developmental tests with their school upon entry. (38)

### For education/healthcare professionals

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<table>
<thead>
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<tbody>
<tr>
<td>5.</td>
<td>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)</td>
<td>A (High quality) Guideline&lt;br&gt;B (High quality)</td>
</tr>
</tbody>
</table>

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

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<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>7.</td>
<td>A unit guideline on screening for developmental problems and school readiness is available and regularly updated.</td>
<td>B (High quality) Guideline</td>
</tr>
</tbody>
</table>

8. Training on standardised screening for developmental problems and poor school readiness is ensured. | B (High quality) Training documentation |

### For health and education services

<p>| | | |</p>
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>9.</td>
<td>A national guideline on screening for developmental problems and school readiness is available and regularly updated.</td>
<td>B (High quality) Guideline</td>
</tr>
</tbody>
</table>

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 |
### Further development

<table>
<thead>
<tr>
<th>For parents and family</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide funding for disadvantaged families to participate in screening services. (39–41)</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>• Provide resources to encourage parents to participate in their child’s educational support planning. (39–41)</td>
<td>A (High quality)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For education/healthcare professionals</th>
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</thead>
<tbody>
<tr>
<td>• Develop teaching methods and strategies that help provide tailored support for very preterm children in the classroom. (30)</td>
<td>A (High quality)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For neonatal unit, hospital, and follow-up team</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>N/A</td>
<td>B (High quality)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For health services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Establish system for data sharing between education and health providers.</td>
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</tbody>
</table>

### Getting started

#### Initial steps

<table>
<thead>
<tr>
<th>For parents and family</th>
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</tr>
</thead>
<tbody>
<tr>
<td>• Parents are informed by healthcare professionals about the importance of developmental screening and assessment, and the sharing of information with schools and education professionals.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For education/healthcare professionals</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Define what school readiness entails according to national or regional policies and identify age-appropriate screening tools or formal tests.</td>
<td></td>
</tr>
<tr>
<td>• Attend training on standardised screening for developmental problems and poor school readiness (professionals providing follow-up and screening services).</td>
<td></td>
</tr>
<tr>
<td>• Attend training on providing feedback and advice on educational needs.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For neonatal unit, hospital, and follow-up team</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Develop and implement a guideline on screening for developmental problems and school readiness.</td>
<td></td>
</tr>
<tr>
<td>• Develop information on follow-up including developmental screening and assessment of school readiness for parents.</td>
<td></td>
</tr>
<tr>
<td>• Establish a clinical pathway from discharge to screening at 6-12 months prior to school entry.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For health service</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Develop and implement a national guideline on screening for developmental problems and school readiness.</td>
<td></td>
</tr>
<tr>
<td>• Initiate data linkage between health and education service providers.</td>
<td></td>
</tr>
<tr>
<td>• Explore legal guidelines and parental consent framework.</td>
<td></td>
</tr>
</tbody>
</table>
Sources


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).


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, van Wassenaer-Leemhuis A

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For parents and family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including screening for mental health difficulties. (1,24)</td>
<td>A (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td></td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td>A (Moderate quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>3. Children identified at risk are offered referral to the appropriate healthcare service (with parental consent).</td>
<td>B (High quality)</td>
<td>Audit report</td>
</tr>
<tr>
<td>4. Parents are asked to consent to share the results of their child’s screening tests with education services.</td>
<td>B (Moderate quality)</td>
<td>Parent consent</td>
</tr>
<tr>
<td><strong>For healthcare professionals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. A unit guideline on follow-up programme including mental health is adhered to by all healthcare professionals.</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>6. Country specific test norms are applied when interpreting the results of screening tests. (25)</td>
<td>A (High quality)</td>
<td>Training documentation</td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality)</td>
<td>Training documentation</td>
</tr>
<tr>
<td></td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>8. Screening using standardised parent-report tools is carried out. (26,27)</td>
<td>A (High quality)</td>
<td>Audit report</td>
</tr>
<tr>
<td><strong>For neonatal unit and follow-up team</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. A unit guideline on follow-up programme including mental health is available and regularly updated.</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
</tbody>
</table>
10. A follow-up programme after discharge including mental health is funded and supported. (28,29)
   A (High quality)  B (Moderate quality)

11. Follow-up rates are continuously monitored.
   B (Moderate quality)

12. Mental health outcomes are used for staff feedback.
   B (Moderate quality)

For hospital and follow-up team
13. Training on standardised mental health assessments is ensured.
   B (High quality)

For health service
14. A national guideline on follow-up programme including mental health is available and regularly updated.
   B (High quality)

15. A follow-up service including mental-health is specified, funded and monitored.
   B (Moderate quality)

Where to go – further development of care

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


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citation
Motor and neurological follow-up assessment

Hadders-Algra M, Vollmer B, van Wassenaer-Leemhuis A, Wolke D

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including screening for neuromotor developmental difficulties. (11,12,19)</td>
<td>A (High quality) B (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>2. Parents are involved in early intervention, e.g., family-centred care. (22–25)</td>
<td>A (High quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>3. Parents receive standardised feedback about the results of their child’s neuromotor health screening in a language that is accessible to them.</td>
<td>B (High quality)</td>
<td>Parent feedback</td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality) B (High quality)</td>
<td>Audit report</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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)</td>
<td>A (High quality) B (High quality)</td>
<td>Audit report, guideline</td>
</tr>
</tbody>
</table>
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 assessment of functional level of gross motor function, manual ability and communication is ensured. (29–34)

<table>
<thead>
<tr>
<th>A (Moderate quality)</th>
<th>B (High quality)</th>
<th>Audit report, guideline</th>
</tr>
</thead>
</table>

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)

<table>
<thead>
<tr>
<th>A (High quality)</th>
<th>B (High quality)</th>
<th>Training documentation</th>
</tr>
</thead>
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<table>
<thead>
<tr>
<th>For neonatal unit, hospital, and follow-up team</th>
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</table>

8. A guideline on the follow-up programme including neuromotor developmental health is available and regularly updated.

<table>
<thead>
<tr>
<th>B (High quality)</th>
<th>Guideline</th>
</tr>
</thead>
</table>

9. Follow-up programme after discharge including neuromotor developmental health is funded and supported.

<table>
<thead>
<tr>
<th>B (Moderate quality)</th>
<th>Audit report</th>
</tr>
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</table>

10. Follow-up rates are continuously monitored.

<table>
<thead>
<tr>
<th>B (Moderate quality)</th>
<th>Audit report</th>
</tr>
</thead>
</table>

11. Neuromotor developmental health outcomes are used for staff feedback.

<table>
<thead>
<tr>
<th>B (Moderate quality)</th>
<th>Audit report</th>
</tr>
</thead>
</table>

12. Training on standardised neuromotor assessments is ensured.

<table>
<thead>
<tr>
<th>B (High quality)</th>
<th>Training documentation</th>
</tr>
</thead>
</table>

13. Appropriate assessment facilities are provided.

<table>
<thead>
<tr>
<th>B (High quality)</th>
<th>Audit report</th>
</tr>
</thead>
</table>

<table>
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<tr>
<th>For health service</th>
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</table>

14. A national guideline on follow-up programme including neuromotor assessment is available and regularly updated.

<table>
<thead>
<tr>
<th>B (High quality)</th>
<th>Guideline</th>
</tr>
</thead>
</table>
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

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

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


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citation
Parent mental health

Houtzager BA, van Wassenaer-Leemhuis A, Wolke D, Virchez M

Target group
Infants born very preterm or those infants with risk factors (see preamble of TEG 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 TEG 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**

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are 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)</td>
<td>A (High quality) B (High quality)</td>
<td>Clinical records, patient information sheet</td>
</tr>
<tr>
<td>2. Parents are supported by early intervention programmes if they are at risk for mental health problems. (27,28) (see TEG Follow-up &amp; continuing care)</td>
<td>A (Moderate quality)</td>
<td>Guideline, parent feedback</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. A guideline on follow-up including parental mental health assessment is adhered to by all healthcare professionals.</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>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 Edinburg Postnatal Depression Scale (EPDS), Hospital Anxiety and Depression Scale (HADS), or Distress Thermometer for Parents (DT-P). (30)</td>
<td>A (Moderate quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>5. Training on recognition of the clinical signs that are associated with mental health difficulties is attended by all responsible healthcare professionals.</td>
<td>B (High quality)</td>
<td>Training records</td>
</tr>
<tr>
<td>6. Parents with identified mental health problems after discharge are referred for locally available specialised mental health support.</td>
<td>B (High quality)</td>
<td>Clinical records</td>
</tr>
</tbody>
</table>
## For neonatal unit, hospital, and follow-up team

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.</td>
<td>A guideline on follow-up including parental mental health assessment is available and regularly updated.</td>
<td>B (High quality)</td>
</tr>
<tr>
<td>8.</td>
<td>Training on recognition of the clinical signs that are associated with mental health difficulties is ensured.</td>
<td>B (High quality)</td>
</tr>
<tr>
<td>9.</td>
<td>A follow-up team (nurse or pediatrician) is available and trained in addressing mental health issues in parents.</td>
<td>B (High quality)</td>
</tr>
</tbody>
</table>

## For health service

<table>
<thead>
<tr>
<th>No.</th>
<th>Description</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.</td>
<td>A national guideline on follow-up including parental mental health assessment is available and regularly updated.</td>
<td>B (High quality)</td>
</tr>
</tbody>
</table>

### Where to go – further development of care

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td>N/A</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
</tr>
<tr>
<td>• Create awareness about the father's mental health.</td>
<td>B (High quality)</td>
</tr>
<tr>
<td>• Improve existing support programmes with extra modules for parent mental health specifically in at-risk/socioeconomically deprived populations.</td>
<td>A (Moderate quality)</td>
</tr>
<tr>
<td>• Generate a greater understanding of the mental health needs of the father.</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>• Provide access to information about parent mental health in a child record.</td>
<td>B (High quality)</td>
</tr>
<tr>
<td>For neonatal unit, hospital, and follow-up team</td>
<td></td>
</tr>
<tr>
<td>• Establish a continuous chain of psychological support before and after discharge.</td>
<td>A (Moderate quality)</td>
</tr>
<tr>
<td>• Facilitate home visits of targeted families, home visits after discharge for families at high medical and social risk.</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>For health service</td>
<td></td>
</tr>
<tr>
<td>• 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.</td>
<td>A (Moderate quality)</td>
</tr>
<tr>
<td>• Generate a greater understanding of the mental health needs of the father.</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>• Provide access to information about parent mental health in a child record.</td>
<td>B (High quality)</td>
</tr>
</tbody>
</table>
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


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citations
Peer and sibling relationships

Vaillancourt T, Hymel S, Wolke D, van Wassenaer-Leemhuis A

Target group
Infants born very preterm or those infants with risk factors (see preamble TEG 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**

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

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

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


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


Target group
Infants born very preterm or those infants with risk factors (see preamble of TEG 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

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

8. A national guideline on early post-discharge responsive parenting programmes is available and regularly updated.  

9. Appropriate funding for early post-discharge responsive parenting programmes is provided. (23–27)

10. Uptake of early post-discharge responsive parenting programmes is monitored.  

Where to go – further development of care

Further development

For parents and family
- Consider post-discharge parenting programmes for other vulnerable groups of children, starting with moderately preterm infants. (23–27)  

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)

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.

For health service
- Encourage studies that develop more individualised responsive parenting programmes. (30)

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.


First edition, November 2018

Lifecycle
5 years/next revision: 2023

Recommended citation
Reproductive counselling

Prefumo F, Johnson MR, van Wassenaer-Leemhuis A, 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

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

8. A national 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)

9. Funding for follow-up care of mothers and for targeted antenatal care in future pregnancies is provided, or included in insurance packages.

Where to go – further development of care

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td>N/A</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td>N/A</td>
</tr>
<tr>
<td>For neonatal unit, hospital, and follow-up team</td>
<td>N/A</td>
</tr>
<tr>
<td>For health service</td>
<td>N/A</td>
</tr>
</tbody>
</table>

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

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, van Wassenaer-Leemhuis A, Wolke D, Parikka V

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

User group
Healthcare professionals, 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 adolescence. (5–8) At school age, asthma medication is prescribed in up to one third of children born very preterm. (5,8,9) Respiratory disorders, including wheezing during respiratory infections, has been shown to be the most common reason for rehospitalisation in very preterm infants. (10–12)

Those born smallest or most immature or with more severe pulmonary problems during the first hospitalisation (having a diagnosis of bronchopulmonary dysplasia) are more likely to have later respiratory problems. (7,9,11,13,14) 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.

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) Physical training in childhood is known to improve cardiopulmonary fitness. (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 rehospitalisations (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

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents, family and children and adults born preterm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents and families are informed about and invited by healthcare</td>
<td>A (High quality)</td>
<td>Patient information sheet</td>
</tr>
<tr>
<td>professionals to attend follow-up programmes including respiratory</td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>assessment. (1,2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Parents and children get recommendations for healthy lifestyle by</td>
<td>A (High quality)</td>
<td></td>
</tr>
<tr>
<td>healthcare professionals. (1,2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. A unit guideline on follow-up including respiratory care is adhered</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>to by all healthcare professionals.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Training on the appropriate referral and treatment for high-risk</td>
<td>A (High quality)</td>
<td>Training documentation</td>
</tr>
<tr>
<td>infants with respiratory disease and about health promotion including</td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>cessation of household smoking is attended by all responsible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>healthcare professionals. (11,15,16,22)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>For neonatal unit, hospital, and follow-up team</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. A unit guideline on follow-up including respiratory care is available</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>and regularly updated.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Symptomatic individuals are referred to appropriate paediatric</td>
<td>B (Moderate quality)</td>
<td>Clinical records</td>
</tr>
<tr>
<td>respiratory services for longer term surveillance.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Training on the appropriate referral and treatment for high-risk</td>
<td>B (High quality)</td>
<td>Training documentation</td>
</tr>
<tr>
<td>infants with respiratory disease and about health promotion including</td>
<td></td>
<td></td>
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<tr>
<td>cessation of household smoking is ensured.</td>
<td></td>
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<tr>
<td>For health service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. A national guideline on follow-up including respiratory care is</td>
<td>B (High quality)</td>
<td>Guideline</td>
</tr>
<tr>
<td>available and regularly updated.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
9. RSV immunisation is available for infants following neonatal bronchopulmonary dysplasia. (26–28)

Where to go – further development of care

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td>N/A</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td>N/A</td>
</tr>
<tr>
<td>For neonatal unit, hospital, and follow-up team</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>Implement the evidence-based practices about lung protective treatment strategies. (29–31) (see TEG Medical care &amp; clinical practice)</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>Benchmark and make available respiratory outcomes up to adulthood against similar services. (32)</td>
<td>B (Low quality)</td>
</tr>
<tr>
<td>For health service</td>
<td>A (High quality)</td>
</tr>
<tr>
<td>Increase awareness of adverse effects of tobacco use and environmental pollution on respiratory health. (16–18)</td>
<td>B (Low quality)</td>
</tr>
<tr>
<td>Include follow-up information on an electronic healthcare card.</td>
<td>B (Low quality)</td>
</tr>
</tbody>
</table>

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
- 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.


First edition, November 2018

Lifecycle
3 years/next revision: 2021

Recommended citation
Transition from hospital to home

Hüning BM, Härtel C, Wolke D, van Wassenaer-Leemhuis A

Target group
Infants born very preterm or those infants with risk factors (see preamble of TEG 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 re-hospitalisation.

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)

Preterm infants remain highly vulnerable to infections, specifically to vaccination-preventable diseases. (4) To minimise this vulnerability, 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"). (5)

Discharge management (6) 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. (3) Evaluation of discharge readiness has to address the infant as well as the family and community/healthcare system that ensure continuing care. (3)

Successful preparation for discharge improves outcomes of very preterm infants in the transition from hospital to home (7), reduces the length of hospital stay (2,8,9), healthcare usage and costs. (10) Timely, schedule-based vaccination of preterm infants reduces the risk for infectious and respiratory morbidity during childhood. (11,12)

Benefits

Short-term benefits
- Reduced length of hospital stay and costs (2,8,9)
- Reduced risk of hospital-acquired mortality and morbidity (2,3)

Long-term benefits
- Seamless care (13)
- Minimised separation of parents and infant (3)
- Continued family support (3)
- Reduced healthcare visits after discharge (2,8,9)
- Reduced infant mortality and morbidity (14)
- Reduced rate of readmissions (8)
- Increased rate of complete vaccination (consensus)
- Improved parental competence and confidence (13,15)
- Reduced stress for parents and family (7)
- Improved parental mental health (9)
- Improved interdisciplinary cooperation and cross-sectoral collaboration for the benefit of the families (13)
- Reduced healthcare costs and costs for the family (7)

**Components of the standard**

<table>
<thead>
<tr>
<th>Component</th>
<th>Grading of evidence</th>
<th>Indicator of meeting the standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Parents are informed and assisted by healthcare professionals in order to participate in care procedures and decision-making from admission to discharge management. (1,9,16)</td>
<td>A (High quality)</td>
<td>Parent feedback, patient information sheet</td>
</tr>
<tr>
<td></td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>2. Parents are informed by healthcare professionals about: (1,14,17–19)</td>
<td>A (High quality)</td>
<td>Parent feedback, patient information sheet</td>
</tr>
<tr>
<td>- symptoms and signs of illness of their infant and how to respond</td>
<td>B (High quality)</td>
<td></td>
</tr>
<tr>
<td>- the importance of vaccination of infants and their household contacts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- breastfeeding</td>
<td></td>
<td></td>
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<tr>
<td>- safe sleeping environment</td>
<td></td>
<td></td>
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<tr>
<td>- car seat safety</td>
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<tr>
<td>- no smoking environment</td>
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</tr>
<tr>
<td>- follow-up visits for ongoing medical problems, growth, and neurodevelopment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- post-discharge positive parenting intervention programmes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Parents receive ongoing psychosocial support that is adapted to their individual needs and resources. (3,20,21)</td>
<td>A (High quality)</td>
<td>Guideline, parent feedback</td>
</tr>
<tr>
<td>4. Discharge planning includes training and resuscitation for high-risk infants. (3,20,21)</td>
<td>A (High quality)</td>
<td>Training documentation</td>
</tr>
</tbody>
</table>
### For healthcare professionals

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<table>
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</thead>
<tbody>
<tr>
<td>5.</td>
<td>A unit guideline on the management of the transition from hospital to home is adhered to by all healthcare professionals.</td>
<td>B (High quality) Guideline</td>
</tr>
<tr>
<td>6.</td>
<td>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 attended by all responsible healthcare professionals. (1,6,22–24)</td>
<td>A (High quality) Guideline, B (High quality) training documentation</td>
</tr>
<tr>
<td>7.</td>
<td>Healthcare professionals communicate with the primary care physician and provide a written discharge summary. (3)</td>
<td>B (Moderate quality) Clinical records</td>
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<td>8.</td>
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</table>

### For neonatal unit, hospital, and follow-up team

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<tbody>
<tr>
<td>9.</td>
<td>A unit guideline on the management of the transition from hospital to home is available and regularly updated.</td>
<td>B (High quality) Guideline</td>
</tr>
<tr>
<td>10.</td>
<td>A multidisciplinary meeting is arranged for each high-risk infant prior to discharge. (3,8)</td>
<td>A (Moderate quality) Guideline, B (Moderate quality)</td>
</tr>
<tr>
<td>11.</td>
<td>Discharge planning is continuously assessed from admission. (8,23)</td>
<td>A (Moderate quality) Clinical records, guideline</td>
</tr>
<tr>
<td>12.</td>
<td>Regular meetings to discuss parental participation and competencies, family, and social issues are organised. (3,8)</td>
<td>A (Moderate quality) Clinical records, guideline</td>
</tr>
<tr>
<td>13.</td>
<td>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.</td>
<td>B (High quality) Guideline, training documentation</td>
</tr>
<tr>
<td>14.</td>
<td>Rooms and equipment for counselling/training of parents are available.</td>
<td>B (High quality) Audit report</td>
</tr>
</tbody>
</table>


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

<table>
<thead>
<tr>
<th>Further development</th>
<th>Grading of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents and family</td>
<td></td>
</tr>
<tr>
<td>• Offer a family-centred care programme with follow-up home visits. (8,25) (See TEG Follow-up &amp; continuing care)</td>
<td>A (High quality) B (Moderate quality)</td>
</tr>
<tr>
<td>For healthcare professionals</td>
<td></td>
</tr>
<tr>
<td>• Offer special education and skills to follow-up team, e.g. case management, communication, social work. (8)</td>
<td>B (High quality)</td>
</tr>
<tr>
<td>For neonatal unit, hospital, and follow-up team</td>
<td></td>
</tr>
<tr>
<td>• Provide support services for siblings. (3,26)</td>
<td>B (Low quality)</td>
</tr>
<tr>
<td>• Enable residence facilities for families. (13,27,28)</td>
<td>B (Low quality)</td>
</tr>
<tr>
<td>For health service</td>
<td></td>
</tr>
<tr>
<td>• Provide framework enabling parents to be with their infants (e.g. parental leave, financial support for travelling, accommodation). (29)</td>
<td>B (Low quality)</td>
</tr>
</tbody>
</table>

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, and car seats).
• Participation of parents is supported (train 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.
• 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). In principle, vaccination of mothers during pregnancy could help to protect infants from birth until immunity is induced by active vaccination for pertussis. (5) A study showed that cocooning was accepted by and successfully implemented among postpartum women in the United States. (30) An alternative approach would be to add general adolescent or adult booster vaccination programmes to existing childhood vaccination programmes. Seasonal influenza vaccination of pregnant women is associated with reduced risk for preterm birth and respiratory morbidity in the offspring. (31)
• Community/healthcare system: development of a comprehensive home care plan, 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) (7,23)
• Counselling (vaccination, safe sleeping environment, household smoking, safe usage of car seat, follow-up visits) complete (3)
• Home environment prepared (7)
• On-going family support programme (if available)

C. COMMUNITY/HEALTHCARE SYSTEM

• Primary care and medical special care physicians informed (1,23)
• Appointments for follow-up visits arranged and confirmed
• Written summary of hospital course, recommendations and home care plan (3,23)
• 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)
• 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 (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

Parents or legal guardians need to ensure that family members/household contacts are up-to-date regarding their vaccinations (e.g. pertussis boosters). Very preterm infants need to be immunised according to the recommended vaccination schedule (see national guideline) based on their chronological age as opposed to their corrected age. Concerns which have caused inadequate or delayed immunisations of preterm infants in the past (e.g., fear of adverse reactions, poor levels of protective antibody responses after vaccinations, lack of adequate muscle mass for injections) have not been found to be valid. (4) Preterm infants generally tolerate vaccinations well and their protective antibody responses are comparable to those seen in term infants. (12) Due to the increased risk of apnoea, bradycardia, respiratory deterioration and suspicion of sepsis in timely association with DTPa-based combined vaccination in extremely preterm infants <28 weeks, it is recommended to administer the first vaccination dose in hospital with a 24-72 h observational period as per national guideline in this most vulnerable group. (38) Subsequent vaccinations should be equally monitored if events occurred during the last vaccination. A detailed vaccination policy is given in table 1. In addition to that, families
need to be well informed about non-specific preventive measures, e.g. use of good hand washing practices and cough hygiene, breastfeeding, and avoiding exposure to smoke, contact with ill persons especially those with respiratory symptoms and unnecessary exposure to crowd.

Table 1: Vaccination policy to be adapted according to specific national guidelines

<table>
<thead>
<tr>
<th>Infant’s age</th>
<th>Vaccination</th>
<th>Route</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-8 weeks</td>
<td>Diphtheria, tetanus, pertussis (whooping cough), polio, Hib (DTaP/IPV/Hib) + Hepatitis B</td>
<td>i.m.</td>
<td>All infants receive vaccinations as per national guidelines. For infants &lt;28 weeks of gestation: administer first vaccination in hospital and observe for at least 24 hours as per national guideline; consider hospitalisation for subsequent dose if events (apnoea, bradycardia, respiratory deterioration, sepsis work-up) occurred</td>
</tr>
<tr>
<td></td>
<td>Pneumococcal disease (PCV, 13-valent)</td>
<td>i.m.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rotavirus (RV)</td>
<td>oral</td>
<td></td>
</tr>
<tr>
<td>10-12 weeks</td>
<td>Diphtheria, tetanus, pertussis (whooping cough), polio, Hib (DTaP/IPV/Hib) + Hepatitis B</td>
<td>i.m.</td>
<td>see above</td>
</tr>
<tr>
<td></td>
<td>Pneumococcal disease (PCV)</td>
<td>i.m.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rotavirus</td>
<td>oral</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Meningococcal disease serotype C</td>
<td>i.m.</td>
<td>To be considered according to local epidemiology and national guidelines</td>
</tr>
<tr>
<td>14-16 weeks</td>
<td>Diphtheria, tetanus, pertussis (whooping cough), polio, Hib (DTaP/IPV/Hib) + Hepatitis B</td>
<td>i.m.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pneumococcal disease (PCV)</td>
<td>i.m.</td>
<td></td>
</tr>
<tr>
<td>Seasonal</td>
<td>Influenza vaccine</td>
<td>i.m.</td>
<td>Consider annual vaccination before season from age 6 months, particularly in preterm infants with chronic lung morbidity such as bronchopulmonary dysplasia (BPD)</td>
</tr>
<tr>
<td></td>
<td>RSV passive immune prophylaxis</td>
<td>i.m.</td>
<td>Passive vaccination before discharge prior to the RSV season, then to be continued 1x/month during the RSV season for high-risk groups as determined by national policy.</td>
</tr>
</tbody>
</table>
In infants born to hepatitis B carrier mothers give hepatitis B immunoglobulin (HBIG) and hepatitis B vaccination within 12 hours of birth regardless of birth weight.

Source


36. 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.


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