**Topic Expert Group:** Follow-up and continuing care

**Meeting special needs at school**

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**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 (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>
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</thead>
<tbody>
<tr>
<td>For parents and families</td>
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<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>
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<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>
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<td>3. Parents of children identified at risk for developmental problems or poor school readiness are offered support prior to school entry, and throughout</td>
<td>A (Moderate quality) B (Moderate quality)</td>
<td>Guideline, parent feedback</td>
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</table>
schooling. (31)

4. Parents are asked for consent to share the results of their child’s screening and/or developmental tests with their school upon entry. (38)  

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<thead>
<tr>
<th>For education/healthcare professionals</th>
<th>B (High quality)</th>
<th>Parent consent</th>
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</thead>
<tbody>
<tr>
<td>5. A guideline on screening for developmental problems and poor school readiness, (e.g. attention, cognitive, social-emotional, early academic skills, and sensory processing) carried out 6-12 months prior to school entry is adhered to by all responsible professionals. (8-10,13,15,38)</td>
<td>A (High quality)</td>
<td>Guideline</td>
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<td>B (High quality)</td>
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<td>6. Training on standardised screening for developmental problems and poor school readiness is attended by all responsible professionals.</td>
<td>B (High quality)</td>
<td>Training documentation</td>
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<td>For neonatal unit, hospital, and follow-up team</td>
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<td>7. A unit guideline on screening for developmental problems and school readiness is available and regularly updated.</td>
<td>B (High quality)</td>
<td>Guideline</td>
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<td>8. Training on standardised screening for developmental problems and poor school readiness is ensured.</td>
<td>B (High quality)</td>
<td>Training documentation</td>
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<td>For health and education services</td>
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<td>9. A national guideline on screening for developmental problems and school readiness is available and regularly updated.</td>
<td>B (High quality)</td>
<td>Guideline</td>
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<td>10. Pathways and a legal framework are established for obtaining parental consent and sharing of information between health and education services.</td>
<td>C (High quality)</td>
<td>Information sharing protocol and legal guidelines</td>
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<td>Further development</td>
<td>Grading of evidence</td>
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<td><strong>For parents and family</strong></td>
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<tr>
<td>• Provide funding for disadvantaged families to participate in screening services. (39–41)</td>
<td>A (High quality)</td>
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<td>• Provide resources to encourage parents to participate in their child’s educational support planning. (39–41)</td>
<td>A (High quality)</td>
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<td><strong>For education/healthcare professionals</strong></td>
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<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>
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<tr>
<td><strong>For neonatal unit, hospital, and follow-up team</strong></td>
<td>N/A</td>
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<td><strong>For health services</strong></td>
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<td>• Establish system for data sharing between education and health providers.</td>
<td>B (High quality)</td>
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**Getting started**

**Initial steps**

**For parents and family**

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

**For education/healthcare professionals**

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

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

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

**For health service**

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


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Lifecycle
5 years/next revision: 2023

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