



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

*Title*

**Cognitive development**

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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, 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*

| <b>Component</b>  | <b>Grading of evidence</b>           | <b>Indicator of meeting the standard</b> |
|---|--------------------------------------|--|
| <b>For parents and family</b>   |                                      |  |
| 1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including cognitive assessments. (19) | A (High quality)<br>B (High quality) | Patient information sheet                |
| 2. Parents receive standardised feedback about the results of the cognitive assessments in language that is accessible to them. (19)      | A (High quality)                     | Parent feedback                          |
| 3. Parents are asked to consent to use routine information from the school to include in outcome measures of cognitive impairment. (19)   | A (High quality)                     | Completed consent                        |
| <b>For healthcare professionals</b>   |                                      |  |
| 4. Country specific test norms are applied when interpreting the results of screening tests. (20)   | A (High quality)                     | Guideline                                |
| 5. A unit guideline on follow-up programme including cognitive assessment is adhered to by all healthcare professionals.                  | B (High quality)                     | Guideline                                |
| 6. Training on standardised cognitive assessments, in which gestational   | A (High quality)<br>B (High quality) | Training documentation                   |



age and first language are taken into account is attended by all responsible healthcare professionals. (8,21–23)

| 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)<br>B (Moderate quality) | Audit report           |
| 10. Appropriate assessment rooms and facilities are available (hospital or provider). (19)                         | A (High quality)<br>B (Moderate quality) | Audit report           |
| 11. Follow-up rates are continuously monitored. (19)   | A (High quality)<br>B (Moderate quality) | Audit report           |
| 12. Cognitive outcomes are used for staff feedback. (19)   | A (High quality)<br>B (Moderate quality) | Audit report           |
| For health service   |  |                        |
| 13. A national guideline on follow-up programme including cognitive assessment is available and regularly updated. | B (High quality)                         | Guideline              |
| 14. A cognitive follow-up service is specified, funded and monitored.  | B (High quality)                         | Audit report           |

*Where to go – further development of care*

| Further development   | Grading of evidence  |
|---|----------------------|
| For parents and family  |                      |
| • Cognitive follow-up at transition to secondary/high-school age is offered.          | B (Moderate quality) |
| • Parents are supported by a case manager. (26) (see TEG Follow-up & continuing care) | A (High quality)     |
| • Incentives to attend follow-up programmes are provided. (2,19,27)                   | A (High quality)     |



For healthcare professionals

N/A

For neonatal unit and follow-up team

- Establish an integrated electronic system with cognitive follow-up provider to schedule follow-up visits. B (Low quality)

For hospital and follow-up team

- Dedicate an assessment facility. B (Moderate quality)

For health service

- Develop a national network for benchmarking of follow-up outcomes. (28,29) A (High quality)
- Include follow-up information on an electronic healthcare card. B (Low quality)

### *Getting started*

#### **Initial steps**

For parents and family

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

For healthcare professionals

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

For neonatal unit and follow-up team

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

For hospital and follow-up team

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

For health service

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

### *Source*

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First edition, November 2018

*Lifecycle*

5 years/next revision: 2023



european standards of  
care for newborn health

*Recommended citation*

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