european standards of
care for newborn health

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

Assessment of visual function

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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 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

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Long-term benefits

- Early diagnosis of visual impairment promotes timely interventions (9)
- Promotes realistic expectations in those with severe impairment (consensus)
- Improved decision making for schooling and learning support (consensus)
- Provides feedback to perinatal and neonatal services and healthcare officials (consensus)
- Reduced risk of misdiagnoses (e.g. reading difficulties) (consensus)
- Improved parent-infant interaction adapted to visual ability (consensus)
- Improved academic outcome (10)
- Improved social integration and quality of life (2)
- Reduced social burden and costs (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed about and invited by healthcare professionals to attend follow-up programme including visual assessments (including ages at which visual follow-up takes place and the provider thereof). (2)	A (High quality) B (High quality)	Patient information sheet
2. Parents receive standardised feedback about the results of their child's visual health screening in a language that is accessible to them.	B (High quality)	Parent feedback
3. Parents are informed about the need for early intervention and support in case of visual impairments.	B (High quality)	Patient information sheet
4. Parents are asked for permission to allow their child's medical and educational information to be used for outcome measures.	B (Low quality)	Parent consent, patient information sheet
5. Parents are asked to consent to share the results of their child's visual screening tests with education services.	B (Moderate quality)	Parent consent
For healthcare professionals		
6. A guideline on follow-up programme including visual assessment is adhered to by all healthcare professionals.	B (High quality)	Guideline
7. Training on standardised visual assessment in high-risk infants in which	A (High quality) B (High quality)	Training documentation

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

Where to go – further development of care

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

Getting started

Initial steps
For parents and family
• Parents are informed by healthcare professionals about the risks to vision after high-risk birth and about the follow-up programme.
For healthcare professionals
• Attend appropriate training on standardised visual assessment. • Establish a structure of communication with other healthcare institutions, providing follow-up care.
For neonatal unit and follow-up team
• Develop and implement a guideline on follow-up programme including visual assessment. • Develop information material about importance of visual follow-up assessment for parents. • Establish at least a formal system of keeping track of families. • Develop a structure of follow-up locally.
For hospital and follow-up team
• Support healthcare professionals to participate in training on standardised visual assessments. • Ensure ophthalmologists are available and trained in visual sequelae of high-risk births.

For health service

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

Description

Retinopathy of prematurity (ROP) is an important cause of visual impairment in the preterm infant, and is due to disorganized vascular development of the retina usually after retinal ischaemia consequent to oxygen exposure. Infants who develop ROP are at increased risk of ophthalmological deficits such as refractive error (up to 64%), amblyopia and strabismus (36-44%). (17) However, these disorders are also prevalent in those born under 32 weeks without ROP, in whom refractive errors are present in 26% of infants, amblyopia in 21% and strabismus in 16-20%. (11) In preterm children attending mainstream school, decreased visual acuity was reported to occur two to three times more frequently than in term-born peers, principally due to refractive errors. High myopia and anisometropia, in particular, confer a risk for developing amblyopia and strabismus. Such early reductions of visual acuity are reportedly subject to “catch-up” by age 5 years, following timely treatment. (17) Weight at birth, head circumference at birth and head circumference at 5,5 years seem to be important contributing factors. (18)

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

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

Source

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