



Topic Expert Group: Follow-up and continuing care

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

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



10. A follow-up programme after discharge including mental health is funded and supported. (28,29)	A (High quality) B (Moderate quality)	Audit report
11. Follow-up rates are continuously monitored.	B (Moderate quality)	Audit report
12. Mental health outcomes are used for staff feedback.	B (Moderate quality)	Audit report

For hospital and follow-up team

13. Training on standardised mental health assessments is ensured.	B (High quality)	Training documentation
--	------------------	------------------------

For health service

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

Where to go – further development of care

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



Getting started

Initial steps

For parents and family

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

For healthcare professionals

- Attend training on standardised mental health assessments.
- Identify an appropriate parent-completed behavioural screening questionnaire that has nationally established norms for use.
- Institute a training programme and standard schedule of assessment.
- Establish a structure of communication with other healthcare institutions, providing follow-up care.

For neonatal unit and follow-up team

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

For hospital and follow-up team

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

For health service

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

Source

1. Johnson S, Marlow N. Preterm birth and childhood psychiatric disorders. *Pediatr Res.* 2011 May;69(5 Pt 2):11R–8R.
2. Lindström K, Lindblad F, Hjern A. Psychiatric morbidity in adolescents and young adults born preterm: a Swedish national cohort study. *Pediatrics.* 2009 Jan;123(1):e47-53.
3. Hille ET, den Ouden AL, Saigal S, Wolke D, Lambert M, Whitaker A, et al. Behavioural problems in children who weigh 1000 g or less at birth in four countries. *Lancet Lond Engl.* 2001 May 26;357(9269):1641–3.
4. Farooqi A, Hägglöf B, Sedin G, Gothefors L, Serenius F. Mental health and social competencies of 10- to 12-year-old children born at 23 to 25 weeks of gestation in the 1990s: a Swedish national prospective follow-up study. *Pediatrics.* 2007 Jul;120(1):118–33.
5. Burnett AC, Anderson PJ, Cheong J, Doyle LW, Davey CG, Wood SJ. Prevalence of psychiatric diagnoses in preterm and full-term children, adolescents and young adults: a meta-analysis. *Psychol Med.* 2011 Dec;41(12):2463–74.
6. Scott MN, Taylor HG, Fristad MA, Klein N, Espy KA, Minich N, et al. Behavior disorders in extremely preterm/extremely low birth weight children in kindergarten. *J Dev Behav Pediatr JDBP.* 2012 Apr;33(3):202–13.



7. Johnson S, Hollis C, Kochhar P, Hennessy E, Wolke D, Marlow N. Psychiatric disorders in extremely preterm children: longitudinal finding at age 11 years in the EPICure study. *J Am Acad Child Adolesc Psychiatry*. 2010 May;49(5):453–463.e1.
8. Spittle AJ, Treyvaud K, Doyle LW, Roberts G, Lee KJ, Inder TE, et al. Early emergence of behavior and social-emotional problems in very preterm infants. *J Am Acad Child Adolesc Psychiatry*. 2009 Sep;48(9):909–18.
9. Reijneveld SA, de Kleine MJK, van Baar AL, Kollée LAA, Verhaak CM, Verhulst FC, et al. Behavioural and emotional problems in very preterm and very low birthweight infants at age 5 years. *Arch Dis Child Fetal Neonatal Ed*. 2006 Nov;91(6):F423–8.
10. Delobel-Ayoub M, Arnaud C, White-Koning M, Casper C, Pierrat V, Garel M, et al. Behavioral problems and cognitive performance at 5 years of age after very preterm birth: the EPIPAGE Study. *Pediatrics*. 2009 Jun;123(6):1485–92.
11. Delobel-Ayoub M, Kaminski M, Marret S, Burguet A, Marchand L, N'Guyen S, et al. Behavioral outcome at 3 years of age in very preterm infants: the EPIPAGE study. *Pediatrics*. 2006 Jun;117(6):1996–2005.
12. Treyvaud K, Doyle LW, Lee KJ, Roberts G, Lim J, Inder TE, et al. Social–Emotional Difficulties in Very Preterm and Term 2 Year Olds Predict Specific Social–Emotional Problems at the Age of 5 Years. *J Pediatr Psychol*. 2012 Aug 1;37(7):779–85.
13. Treyvaud K, Ure A, Doyle LW, Lee KJ, Rogers CE, Kidokoro H, et al. Psychiatric outcomes at age seven for very preterm children: rates and predictors. *J Child Psychol Psychiatry*. 2013 Jul;54(7):772–9.
14. Johnson S, Kochhar P, Hennessy E, Marlow N, Wolke D, Hollis C. Antecedents of Attention-Deficit/Hyperactivity Disorder Symptoms in Children Born Extremely Preterm. *J Dev Behav Pediatr JDBP*. 2016 May;37(4):285–97.
15. Breeman LD, Jaekel J, Baumann N, Bartmann P, Wolke D. Attention problems in very preterm children from childhood to adulthood: the Bavarian Longitudinal Study. *J Child Psychol Psychiatry*. 2016 Feb;57(2):132–40.
16. Gray RF, Indurkha A, McCormick MC. Prevalence, stability, and predictors of clinically significant behavior problems in low birth weight children at 3, 5, and 8 years of age. *Pediatrics*. 2004 Sep;114(3):736–43.
17. Ure AM, Treyvaud K, Thompson DK, Pascoe L, Roberts G, Lee KJ, et al. Neonatal brain abnormalities associated with autism spectrum disorder in children born very preterm. *Autism Res Off J Int Soc Autism Res*. 2016;9(5):543–52.
18. Indredavik MS, Vik T, Heyerdahl S, Kulseng S, Brubakk A-M. Psychiatric symptoms in low birth weight adolescents, assessed by screening questionnaires. *Eur Child Adolesc Psychiatry*. 2005 Jul;14(4):226–36.
19. Heinonen K, Räikkönen K, Pesonen A-K, Andersson S, Kajantie E, Eriksson JG, et al. Behavioural symptoms of attention deficit/hyperactivity disorder in preterm and term children born small and appropriate for gestational age: a longitudinal study. *BMC Pediatr*. 2010 Dec 15;10:91.
20. Johnson S, Hollis C, Marlow N, Simms V, Wolke D. Screening for childhood mental health disorders using the Strengths and Difficulties Questionnaire: the validity of multi-informant reports. *Dev Med Child Neurol*. 2014 May;56(5):453–9.
21. Briggs-Gowan MJ, Carter AS. Social-emotional screening status in early childhood predicts elementary school outcomes. *Pediatrics*. 2008 May;121(5):957–62.
22. Lemer C. Annual report of the Chief Medical Officer 2012: our children deserve better: prevention pays. 2013;



23. Johnson S, Gilmore C, Gallimore I, Jaekel J, Wolke D. The long-term consequences of preterm birth: what do teachers know? *Dev Med Child Neurol*. 2015 Jun;57(6):571–7.
24. Johnson S, Wolke D. Behavioural outcomes and psychopathology during adolescence [Internet]. 2013 [cited 2018 Jun 15]. Available from: <https://www.sciencedirect.com/science/article/pii/S0378378213000236>
25. Westera JJ, Houtzager BA, Overdiek B, van Wassenaer AG. Applying Dutch and US versions of the BSID-II in Dutch children born preterm leads to different outcomes. *Dev Med Child Neurol*. 2008 Jun;50(6):445–9.
26. Johnson S, Wolke D, Marlow N. Outcome monitoring in preterm populations - Measures and methods. *Z Für Psychol J Psychol*. 2008 Jan 1;216(3):135–46.
27. Drotar D, Stancin T, Dworkin PH, Sices L, Wood S. Selecting developmental surveillance and screening tools. *Pediatr Rev*. 2008 Oct;29(10):e52-58.
28. Hille ETM, Elbertse L, Gravenhorst JB, Brand R, Verloove-Vanhorick SP, Dutch POPS-19 Collaborative Study Group. Nonresponse bias in a follow-up study of 19-year-old adolescents born as preterm infants. *Pediatrics*. 2005 Nov;116(5):e662-666.
29. Wolke D, Söhne B, Ohrt B, Riegel K. Follow-up of preterm children: important to document dropouts. *The Lancet*. 1995 Feb 18;345(8947):447.
30. Relton C, Strong M, Thomas KJ, Whelan B, Walters SJ, Burrows J, et al. Effect of Financial Incentives on Breastfeeding: A Cluster Randomized Clinical Trial. *JAMA Pediatr*. 2018 Feb 5;172(2):e174523.
31. Hüning BM, Reimann M, Beerenberg U, Stein A, Schmidt A, Felderhoff-Müser U. Establishment of a family-centred care programme with follow-up home visits: implications for clinical care and economic characteristics. *Klin Pädiatr*. 2012 Nov;224(7):431–6.
32. Kallioinen M, Eadon H, Murphy MS, Baird G, Guideline Committee. Developmental follow-up of children and young people born preterm: summary of NICE guidance. *BMJ*. 2017 10;358:j3514.
33. Wang CJ, McGlynn EA, Brook RH, Leonard CH, Piecuch RE, Hsueh SI, et al. Quality-of-care indicators for the neurodevelopmental follow-up of very low birth weight children: results of an expert panel process. *Pediatrics*. 2006 Jun;117(6):2080–92.
34. Mercier CE, Dunn MS, Ferrelli KR, Howard DB, Soll RF, Vermont Oxford Network ELBW Infant Follow-Up Study Group. Neurodevelopmental outcome of extremely low birth weight infants from the Vermont Oxford network: 1998-2003. *Neonatology*. 2010 Jun;97(4):329–38.

First edition, November 2018

Lifecycle

5 years/next revision: 2023

Recommended citation

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