NICE guidance for developmental follow-up of children born preterm

The National Institute of Health and Care Excellence (NICE) guideline *Developmental Follow-up of Children and Young People Born Preterm* highlights potential risk factors to infant development and recommends enhanced surveillance and monitoring for infants born at less than 28 weeks' gestation once discharged from the neonatal unit until four years uncorrected age. The guideline also recognises the importance of being able to provide parents and carers with the best available evidence about the developmental needs of infants born prematurely.

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Key points

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1. Infants born preterm are at high risk of developmental problems and disorders.
2. Enhanced surveillance and support should be offered to all premature infants born below 30 weeks' gestation until two years corrected age.
3. Infants born between 30 and 36 weeks' gestation who have other risk factors should receive enhanced surveillance.
4. Infants born below 28 weeks' gestation are at high risk of poor educational outcomes. In addition to enhanced surveillance and support, they should be assessed at four years uncorrected age.

More premature infants are surviving. The NICE guidance *Developmental Follow-up of Children and Young People Born Preterm* (NICE Guideline NG72)[1] was published in 2017 to provide recommendations for infant follow-up based on the best evidence for identifying risk factors to watch for during early development. It aims to improve outcomes for these children by reducing variation in follow-up and, at the same time, enable benchmarking of neonatal care. It also sets out clear guidance for appropriate surveillance and support post-discharge from the neonatal unit during the pre-school years.

This short report summarises the NICE Guideline NG72, and highlights why it is important for both neonatal unit practitioners and community healthcare services to be aware of the contents of this document.

Bliss, the charity for babies born premature or sick, reports that 60,000 infants born in the UK will be premature.[2] Typically, premature infants are those born below 37 weeks' gestation. Subcategories include:[3]

- extremely preterm (<28 weeks' gestation)
- very preterm (28 to <32 weeks' gestation)
- moderate to late preterm infants (32 to <37 weeks' gestation).

Within these categories infants can additionally be small for their gestational age.[3] The wide span of gestational birth ages and associated risks highlight the potential diversity in terms of ongoing longer-term support for infants born premature. The NICE guideline summarises that infants born prematurely can be at risk of developing a range of motor problems (eg cerebral palsy), executive functioning, learning, speech, language, feeding, eating and drinking difficulties.[1] These problems are related to gestational birth age as well as neonatal, biological and maternal factors.[1] Specific research cited in the guideline identifies risk factors related to a variety of developmental problems and disorders. For example, infants born at less than 28 weeks' gestation are at a high risk of intellectual disabilities and hearing impairment. In addition, severe brain lesions such as intraventricular haemorrhages grade 3 and 4, experienced by infants born at less than 34 weeks' gestation, present an increased risk of developing autistic spectrum conditions. Severe retinopathy of prematurity is associated with an increased risk of motor function problems, visual impairments and, for infants born at <28 weeks' gestation, intellectual disability.

The recommendations state that all preterm infants born before 30 weeks' gestation, and those born between 30 and 36 weeks with specific and identifiable risk factors, should have enhanced support and monitoring up to two years corrected age. Infants born at or before 28 weeks' gestation are offered support and monitoring up to four years uncorrected age because of the increased risks of special educational needs. Responsibilities for educating, supporting and reassuring parents and carers by referring to the best evidence available is an important aspect of the guideline, with identification of care pathways to enable developing infants to receive appropriate intervention and support once they have been discharged from the neonatal unit.

The core team recommended for

enhanced developmental support and surveillance should include a neonatologist or paediatrician who has developed specific knowledge and understanding related to premature infant development and outcomes. In addition there should be a specialist nurse (eg a community nurse or health visitor) along with at least one allied health professional such as a speech and language therapist, physiotherapist and/or occupational therapist. At four years uncorrected age, assessment by either a clinical psychologist or educational psychologist is recommended. Recommended assessment tools are listed for completion at follow-up appointments, for example use of the Parent Report of Children's Abilities – Revised (PARCA–R) at two years corrected age. This parent evaluation includes identification of a child's early play skills (eg object manipulation, symbolic play and pretend play) with some aspects of early language development (ie pointing). The early language section covers first words and the meaning of the communication skills that the child has acquired at the time of assessment.

The guideline quite rightly raises the issue that the impact of having a premature infant can have profound emotional and psychological ramifications for parents and carers. With this in mind it seems appropriate that neonatal unit staff should be aware of and have access to the guideline on the unit so that parents can receive informed feedback and information when asking questions about their infant's future development. A clear summary is also available in the *BMJ*, which neonatal staff may find helpful.[4]

Aside from providing advice for parents and carers, the guideline should also encourage nurses and therapists on neonatal units to reflect on the intervention strategies they use in the early stages of infant care and to enable parents to continue to build on these to maximise their child's developmental potential once they leave the unit (**TABLE 1**). It is important that practitioners can inform parents of potential outcomes in future development when they are on the neonatal unit and the type of monitoring and support they might receive. In addition, nursing and therapy practitioners can be advocates for the infants and families they work with to ensure successful transition from a neonatal unit to local community services. This should help and support the follow-up recommended in the guideline.

Strategy	Benefits
1. Neonatal individualised developmental care[5]	Benefits include neurobehavioural functioning, stability and infant regulation of both autonomic and motor systems. Parents and carers can gain confidence with managing their infant's interaction with the environment during everyday care.
2. Positioning and observations of motor skills[6,7]	Positioning can help focus parent observations of infant comfort. In addition, parents can learn to observe motor patterns confidently, and therefore become alert to any possible risk factors.
3. Skin-to-skin care out of the incubator[8-10]	Skin-to-skin experiences can help infant physiological stability. Parents can also experience how their infant reacts and therefore they will learn to read and provide confident communication support by being responsive communicators.
4. Pre-feeding and early feeding experiences: Baby Friendly initiatives,[11] interpreting oral readiness signs,[12,13] non-nutritive sucking[14-16]	Parents and carers can receive support and gain confidence when preparing for oral feeding by learning to interpret their infant's hunger and satiation signs. They can also be supported to reduce risks of oral aversions by positive oral experiences. Communication skills can be encouraged during early feeding development.
5. Communication development[12,17]	Supporting parents to interpret infant responses in all functional activities can support parent knowledge of infant preferences, expected responses and regulatory responses. Parent confidence with understanding infant communication style can lead to them developing competent communication partner skills for interaction with their infants. Parents can also be alert to any risk factors associated with communication that may arise.

TABLE 1 Examples of strategies used on the neonatal unit and their importance as baseline skills for professionals and families to build on once an infant is discharged from neonatal care.

References

1. **National Institute of Health Care and Excellence.** Developmental follow-up of children and young people born preterm (NICE Guideline NG72). 2017 Online at: www.nice.org.uk/guidance/ng72
2. **Bliss.** Why we exist. Online at: www.bliss.org.uk/why-we-exist
3. **World Health Organization.** Preterm birth: fact sheet. 2016 Online at: www.who.int/mediacentre/factsheet/fs363/en/
4. **Kallioinen M, Eadon H, Murphy MS, Baird G.** Developmental follow-up of children and young people born preterm: summary of NICE guidance. BMJ 2017;358:j3541.
5. **Als H, Gilkerson L, Duffy FH, et al.** A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: medical, neurodevelopmental, parenting and caregiving effects. J Dev Behav Pediatr 2003;24:399-408.
6. **Bartlett DJ, Fanning JE.** Use of the Alberta Infant Motor Scale to characterize the motor development of infants born preterm at eight months corrected age. Phys Occup Ther Pediatr 2003;23:31-45.
7. **Madlinger-Lewis L, Reynolds L, Zarem C, et al.** The effects of alternative positioning on preterm infants in the neonatal intensive care unit: a randomized clinical trial. Res Dev Disabil 2015;35:490-97.
8. **Blomqvist YT, Ewald U, Gradin M, et al.** Initiation and extent of skin-to-skin care at two Swedish neonatal intensive care units. Acta Paediatr 2013;102:22-28.
9. **Carbasse A, Kracher S, Hausser M, et al.** Safety and effectiveness of skin-to-skin contact in the NICU to support neurodevelopment in vulnerable preterm infants. J Perinat Neonatal Nurs 2013;27:255-62.
10. **Chan GJ, Labar AS, Wall S, Atun R.** Kangaroo mother care: systematic review of barriers and enablers. Bull World Health Org 2016;94:130-41.
11. **World Health Organization, UNICEF.** Baby Friendly Hospital Initiative: revised, updated and expanded for integrated care. Section 1: background and implementation. Geneva, Switzerland: WHO and UNICEF; 2009.
12. **Brown LF, Pridham K.** The effect of maternal depressive symptoms and early maternal feeding behavior on later infant feeding behavior. Newborn Infant Nurs Rev 2007;7:56-63.
13. **Harding C, Mynard A, Hills E.** Identification of premature infant states in relation to introducing oral feeding. J Neonatal Nurs 2017; doi: 10.1016/j.jnn.2017.11.018.
14. **Harding C, Frank L, Van Someren V, et al.** How does non-nutritive sucking support infant feeding? Infant Behavior and Development 2014;37:457-64.
15. **Harding C, Frank L, Botting N, Hilari K.** Assessment and management of infant feeding. Infant 2015;11:85-89.
16. **Greene Z, O'Donnell CPF, Walshe M.** Oral stimulation for promoting oral feeding in preterm infants. Cochrane Database Syst Rev 2016: CD009720.
17. **Caskey M, Stephens B, Tucker R, Vohr B.** Adult talk in the NICU with preterm infants and developmental outcomes. Pediatrics 2014;133:e578-84.