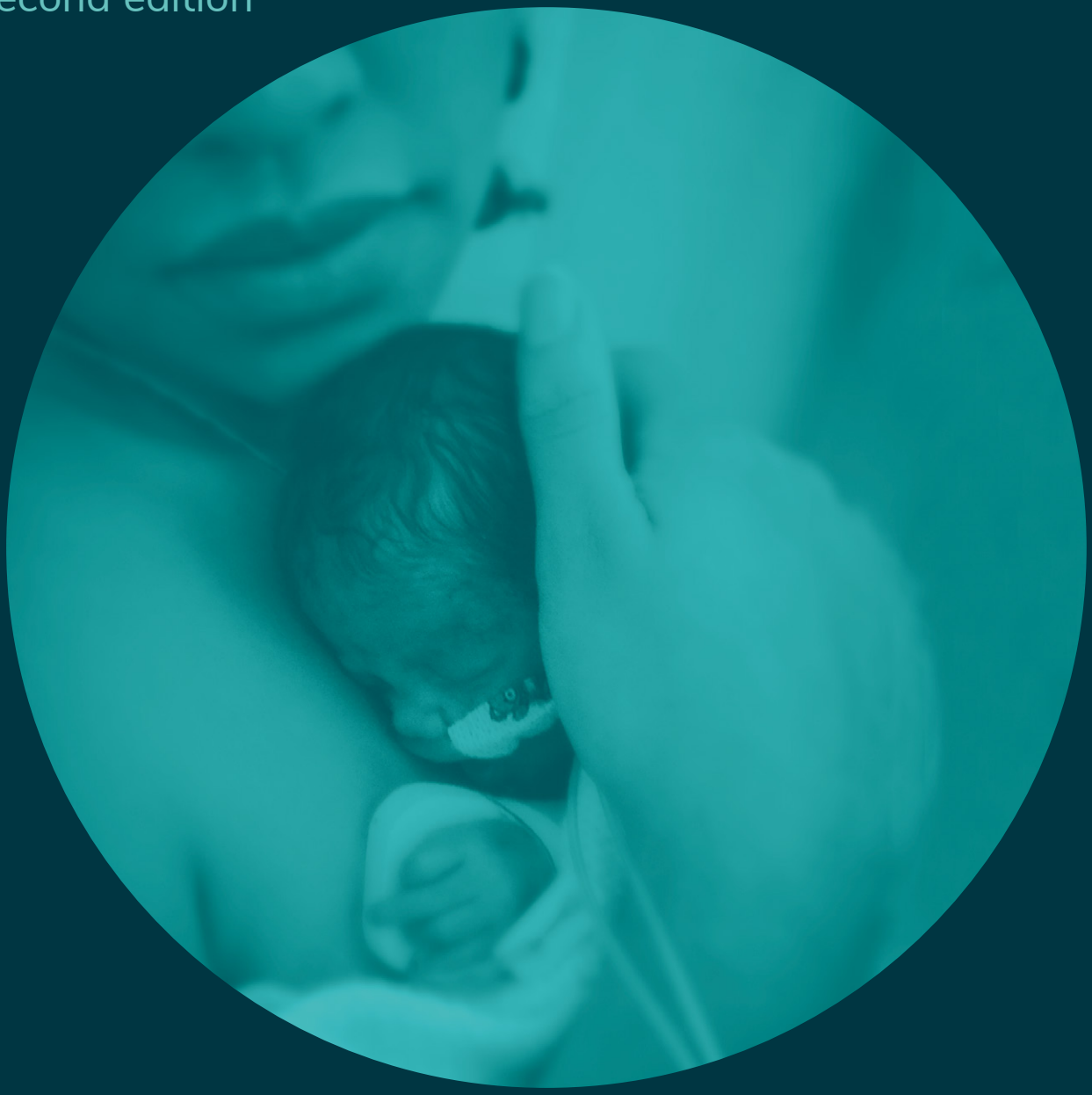
Occupational therapy in neonatal services and early intervention

Practice guideline
Second edition



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An associated document, *Occupational therapy in neonatal services and early intervention: practice guideline supplement – evidence tables* (see Appendix 2) is available to download from the Royal College of Occupational Therapists' website.

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Contents

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The term 'parent', as used in the guideline, should be considered to be inclusive of guardians or caregivers.

This guideline was reviewed using the processes defined within the *Practice guideline development manual, fourth edition* (Royal College of Occupational Therapists [RCOT] 2020).

Readers are referred to the manual to obtain further details of specific stages within the guideline development process, available at:

https://www.rcot.co.uk/node/293

Foreword

Working with children, young people and their families for the last 20 years, I am an occupational therapist to my core. I am also the proud parent of two children born prematurely. Starting out OT life in acute paediatrics, working in neonatal care I thought I knew NICU. And then I became an NICU parent, lost in an uncertain medical world and blindly 'going through the motions' of daily care. I was used to working with tiny babies and anxious parents surrounded by lines, machines and tubes. But as an NICU mum the machines and monitors seemed alien to me, the smallest bump hit me hard, and the sound of alarms and buzzers would stop me in my tracks.

It was two months before we brought our baby home. I was shell shocked and over the coming months and years I began to process the trauma of what we had all been through.

Ten years on I am acutely aware not only of the impact that premature birth has had on the cognitive, sensory and motor development of my 29 weeker but also the impact my own traumatic start to parenthood had on my ability to meet their developmental needs.

As so clearly defined in these guidelines, occupational therapists have a specialist and unique role to play in supporting babies born prematurely and their families, both during and after neonatal care. Their holistic approach to care, as highlighted throughout the document, places emphasis not only on developmental care and early intervention but also on parent engagement and support, understanding the link between the two.

I would like to thank all occupational therapists who have led in this area of work and who have paved the way to establish the role of occupational therapy in neonatal care. Particular thanks go to the guideline development group and authors. I have no doubt that the implementation of the evidence-based recommendations will lead to improved outcomes for children born prematurely and wholeheartedly support the group in ensuring that their recommendations are implemented at every level.

Catriona Ogilvy
Highly Specialist Occupational Therapist and Founder of The Smallest Things

Foreword

Neonatal intensive care is developing and orienting itself towards producing quality outcomes for both the infant and their family. Core to this is the support provided by occupational therapists alongside other allied health professionals as important parts of the neonatal team, ensuring that multidisciplinary care is the bedrock of what we do.

The welcome and timely revision of these guidelines indicates the support for neonatal practice from occupational therapy professionals. It again emphasises the core role of the occupational therapist in supporting the family and the neonatal team in providing developmentally focused and appropriate interventions. Specific allied health professional funding is being provided as part of the NHS Long Term Plan for neonatal care to ensure that integration of this important group into core neonatal practice occurs.

These guidelines span the breadth of neonatal care, from kangaroo mother care to minimising painful interventions, and are supported by a wealth of research data to support neonatal teams in their assessment of the need for such expertise within the team. They also acknowledge the critical importance of taking the mother and family on the journey, so that their input may support and extend the value of the developmentally appropriate advice and support. Multidisciplinary developmental care is critical in delivering improved long-term outcomes, for the baby and for the family, minimising the stress and fear which may interrupt normal rearing practices.

One of the strengths of occupational therapy in a neonatal setting is the ability to support an individual's developmental care after discharge from hospital. In keeping with current guidance, this is suggested to cease two years after discharge but in practice should continue for as long as it is required. Careful assessment and multidisciplinary engagement are important in children for whom there are developmental concerns. The assessment and provision of timely early interventions during infancy is the likely long-term benefit, alongside the avoidance of developmental problems where they can be foreseen. This continuity is highly valued by parents and is a very necessary contribution to ensuring high-quality outcomes.

These guidelines importantly have been developed using the most robust methodology we have and thus represent the state of the art within current knowledge. This ensures that they are of relevance and demonstrate the strong 'need' for such services within neonatal and high-risk follow-up services.

At a time when all National Health Services are under review and scrutiny, such a valuable contribution is to be welcomed. These guidelines provide evidence that occupational therapists should be at the heart of the neonatal team and resourced from within neonatal financial envelopes.

Neil Marlow DM FMedSci
Institute for Women's Health, University College London

Foreword

Babies admitted to neonatal care are often at risk for developmental sequelae, be that a result of a premature birth or a complicated delivery at term. While some children may have significant disability, for others the long-term effects can be subtle and wide ranging, impacting on cognitive, sensory, motor, language and social-emotional development. Developmental difficulties may emerge early in infancy and can persist into adulthood, having a marked impact on children's learning, school performance, mental health and wellbeing. Even infants without significant morbidity in the first few years of life may go on to have subtle difficulties at school age and may benefit from early preventive intervention.

A high-risk birth can also have a major impact on the family as a whole, affecting parents' mental health and wellbeing and their interactions with their child, which may in turn affect children's outcomes. Identifying developmental problems in infancy is therefore crucial in order that families can be supported from the earliest opportunity to ensure that every baby discharged from neonatal care has the best possible start in life. Providing holistic, developmentally supportive care and early intervention is a vital role that occupational therapists play in neonatal care, supporting not just infants and families themselves but also their colleagues by ensuring that development is at the heart of neonatal care.

The publication of the second edition of this guideline reflects both the growing body of evidence around neurodevelopmental assessment and early intervention and the increasing contribution that occupational therapy makes to neonatal care and neurodevelopmental follow up. The guideline development group are to be congratulated on their comprehensive review and appraisal of the literature and the development of robust, evidence-based recommendations, the scope of which reflects the broad impact that occupational therapists make. These include recommendations around the provision of developmentally supportive care, the identification of developmental concerns, the provision of early intervention, and support for parents. In particular, the guideline highlights opportunities for working collaboratively with parents to help nurture their relationship with their child.

This guideline is both important and timely. Investment in children's development should start at birth to provide the building blocks for future health and wellbeing. Recent studies comparing outcomes for consecutive cohorts of extremely preterm born babies have shown little improvement in long-term neurodevelopmental outcomes despite increasing survival over recent decades. This underscores the need to focus on improving the provision of developmental, parental and educational support to optimise infant development from the earliest opportunity, which are at the heart of this guideline. I am sure the guideline will be a major benefit to practitioners and a significant step forward in improving outcomes for this vulnerable group of infants and their families.

Dr Samantha Johnson
Professor of Child Development, Department of Health Sciences, University of Leicester

Introduction

This practice guideline aims to define the best and most effective occupational therapy practice for high-risk[1] infants in neonatal and early intervention settings.

As a primary resource for occupational therapists practising in this area, the guideline can assist decision making about areas for assessment and intervention, in addition to describing the profession's contribution to the neonatal care pathway.

The guideline may also be of use to other neonatal practitioners and commissioners with regards to the inclusion of occupational therapy within neonatal multidisciplinary teams.

Occupational therapy makes a unique contribution to the neonatal team and the services it provides to infants and families. Occupational therapists have specific skills and knowledge that can enhance the delivery of neonatal care:

- Unlike other professions, one of the distinctive characteristics of occupational therapy education is that it incorporates both physical and mental healthcare models, resulting in a holistic approach. This is particularly relevant because preterm infants are at risk of developing emotional and behavioural problems later in life (Mathewson et al 2017). Occupational therapists' particular interest in the antecedents to these issues makes them key contributors to a preventative healthcare model with this client group. In addition, parents/caregivers may experience issues around psychological adjustment, and mental health issues may adversely affect parenting efficacy. Occupational therapists can support their caregivers to develop successful psychological and practical coping strategies for themselves and their infants.

- Preterm infants are at risk of, and often present with, sensory processing problems, which is a specialised area of practice for occupational therapy (Bröring et al 2017). Early sensory and motor exposures lay the building blocks for development and lifelong adaptation as well as for successful parent–child interaction. Occupational therapists can provide a specialist role in educating parents on promoting developmentally appropriate sensory stimulation and experiences for their babies.

- Occupational therapy is based on systems theory models (Reed and Sanderson 1992; Kielhofner 2002), which emphasise that dynamic interactions within families, within the neonatal unit and within the community are part of a problem-solving paradigm.

This guideline refers to the 'occupations' in which infants and parents participate. Occupation is 'the context in which people develop skills, express their feelings, construct relationships, create knowledge and find meaning and purpose in life' (Townsend and Polatajko 2007, xxi). Infant 'occupations' are the activities that they engage in as they strive to master the skills they will need to adapt to their environment, to form close relationships, to learn and to move towards independence. The parent 'occupations' are the activities through which they support their infants' efforts to achieve these goals, providing a nurturing and developmentally appropriate environment with opportunities to master the skills they will need for life. These processes begin at birth and in the newborn period require close synchrony; hence the term 'co-occupations'. (For full definitions of terms used in the guideline, see the glossary in Appendix 1.)

It is recognised that all neonatal healthcare professionals will be expected to have a range of common core skills and that there will be considerable professional overlap (Barbosa 2013). This is

an advantage in the delivery of neonatal care. A transdisciplinary model of teamwork is particularly economical and effective when working with infants, who have a relatively uncomplicated range of abilities compared with adults. This means that the different disciplines can agree to share and overlap in order to simplify services for families. Although different professional roles may overlap, each profession brings to those roles its own perspectives and skills, which add a richness of knowledge and experience to the team. The range of practice for each profession will be influenced by the presence or absence of other allied health professionals and the skills they bring to the team. Individual teams will vary in how widely they collaborate to ensure the provision of developmentally supportive care for infants in their care.

The occupational therapist may not be available daily for families in the same way that a nurse will be, but they can be a resource for nurses and other members of the team to support problem solving and to facilitate individual developmentally supportive care plans. The occupational therapist's primary role is to keep all aspects of development in mind when nurses and doctors may be necessarily focused on the medical and technical challenges around the care of the infant. Occupational therapists come to neonatology with a different set of skills and knowledge, including a long-term perspective on the outcomes for infants and families. Where the multidisciplinary team includes members of different professions with different levels of experience, those that are more senior or more experienced will share knowledge and skills to support those from other professions who are new to this area of work.

In 2020, the COVID pandemic resulted in significant societal changes. Within the UK, a national lockdown and restrictions were implemented that affected all aspects of our lives. Wide-scale restrictions for all inpatient visiting were implemented across NHS services to minimise risk of infection transmission. This included changes to the access of parents and families of infants receiving care in neonatal units. Along with other neonatal providers, occupational therapists had to consider alternative ways to continue to support vulnerable infants and their families when parents were unable to be present. Some e-health methods were already established, such as Baby Diary, vcreate® or web camera systems. Post-discharge from the neonatal unit, many infants in the community were supported with technology such as Attend Anywhere video calls, enabling occupational therapists to see the infant and discuss progress and any issues with parents or carers. Families were able to send videos on mobile apps and vcreate® to allow updating of information on their infant's development. These options enabled the provision of ongoing care during the pandemic. Occupational therapists were able to respond and adapt as necessary to embrace the technology. Internationally, e-health methods are becoming embedded in neonatal services as a potential support where and when required and are likely to continue to be used in conjunction with face-to-face contact as further evidence about e-health emerges. However, it is also important to note that some families have challenges accessing e-health technologies due to a variety of reasons, and occupational therapists must consider the individual needs and situations of families who require a face-to-face model of support to minimise the impact of digital exclusion.

It is acknowledged that evidence of varying levels has been used to develop the recommendations included in this guideline. The quality of the research available is influenced by the limitations of robust randomised trial designs in evaluating complex interventions. This is particularly the case in the neonatal setting where specific interventions are individualised to support each infant's neurobehavioural competencies. Samples included in the studies tend to be heterogeneous and often small due to small numbers of eligible infants and families. Additionally, outcomes over the life course (infancy, childhood, adolescence and adulthood) are likely to be influenced by many unmanageable variables. As described further in the guideline, a formal process of appraising and grading the evidence has been undertaken to enable judicious use of the evidence in developing the recommendations.

Finally, this resource is the first stage in a series of developments. A career development framework for neonatal occupational therapy practice is currently in development. Additionally, a collaborative project is being undertaken with Health Education England for the development of neonatal occupational therapy education modules and pathways at foundation, enhanced and advanced levels of practice. It is anticipated that these developments will add increasing specificity to the provision of occupational therapy services in neonatal settings in the United Kingdom.

Note

1 'High risk' has been used to describe the target population of this guideline, which includes all infants born preterm, high-risk infants born at term (e.g. infants with neonatal hypoxic ischaemic encephalopathy, neonatal abstinence syndrome, congenital conditions or having undergone complex surgical procedures), infants receiving palliative care, and their parents. It is acknowledged that not all infants considered high risk at birth will develop developmental sequelae, but the term 'high risk' is used for brevity.

Key recommendations for implementation

The aim of this guideline is to provide specific evidence-based recommendations which describe the most appropriate care or action to be taken by occupational therapists working in neonatal services or early intervention.

Recommendation statements should not be taken in isolation and must be considered in conjunction with the contextual information provided in this document, together with the details on the strength and quality of the recommendations. The statements are graded based on the Grading of Recommendations Assessment, Development and Evaluation (GRADE) process (GRADE Working Group 2004) as described in the Royal College of Occupational Therapists' *Practice guideline development manual*, fourth edition (RCOT 2020). The strength of the recommendations is identified via a scoring of 1 (strong) or 2 (conditional), and the quality of the supporting evidence via a grading on a scale of A (high) to D (very low). This revised edition of the guideline strengthens the previous recommendations with new evidence, amends seven recommendation statements, and adds five new recommendations for practice.

It is strongly advised that readers study Sections 10 and 11 to understand the guideline methodology, together with the evidence tables (in a supplemental document; details can be found in Appendix 2), to be fully aware of the outcome of the literature search and overall available evidence.

The guideline aims to support the occupational therapist's decision making and clinical reasoning. Being based on evidence, it cannot cover all aspects of occupational therapy in neonatal services or early intervention.

The recommendations for occupational therapy intervention, based on the best available evidence to date, are set out in the following 11 categories:

1. Occupation-based assessment
2. Developmentally supportive care
3. Pain management
4. Skin-to-skin (kangaroo) care
5. Touch
6. Postural support
7. Infant feeding
8. Parent engagement
9. Parent support
10. Identifying developmental concerns
11. Early intervention

In each of the recommendations outlined, the collective term of 'high-risk infant' is used, and includes all infants born preterm, high-risk infants born at term (e.g. infants with hypoxic ischaemic encephalopathy, neonatal abstinence syndrome, congenital conditions or having undergone complex surgical procedures), infants receiving palliative care and their parents.

Recommendations by category

The recommendations are not presented in any order of priority or relative importance. They loosely represent the stages of an infant's journey through a neonatal unit admission and beyond. The overall quality of evidence grade reflects the robustness or type of research supporting a recommendation, but not necessarily the recommendation's significance to occupational therapy practice.

'**It is recommended** ...' Benefits appear to outweigh the risks (or vice versa) for the majority of the target group; most people who access services would want or should receive this course of intervention or action.

'**It is suggested** ...' Risks and benefits are more closely balanced, or there is more uncertainty in the values and preferences of people who are likely to access services; most people who access services would want this intervention but not all, and therefore they should be supported to arrive at a decision for intervention consistent with the benefits and their values and preferences.

Occupation-based assessment	
1. **It is recommended** that occupational therapists safely and appropriately assess the neurobehavioural status of the high-risk infant, in order to plan/deliver developmentally supportive care. (Als et al 2003 [A]; Pineda et al 2020 [B]; El-Dib et al 2011 [C]; Allinson et al 2017 [D]) [New evidence 2022]	1A
2. **It is recommended** that occupational therapists assess neurobehavioural and neurodevelopmental status to provide guidance and identify infants appropriate for developmental follow up following discharge. (Craciunoiu and Holsti 2017 [A]; Bartlett 2003 [C]; Sucharew et al 2012 [C]; Crowle et al 2015 [D]; Liu et al 2010 [D]) [New evidence 2022]	1A
3. **It is recommended** that occupational therapists liaise with community teams and assess neurodevelopmental status for high-risk infants in the first two years of life to provide guidance and implement early intervention services where indicated. (Liu et al 2010 [D])	1D

Developmentally supportive care

4. **It is recommended** that developmentally supportive care principles are implemented for high-risk infants admitted to neonatal units to enhance short-term health and developmental outcomes. (Als et al 2003 [A]; McAnulty et al 2009 [A]; Symington and Pinelli 2006 [A]; Legendre et al 2011 [B]; McAnulty et al 2010 [B]; Oostlander et al 2019 [B]; Soleimani et al 2020 [B]; Wallin and Eriksson 2009 [B]) [New evidence 2022]	1A
5. **It is recommended** that occupational therapists promote an appropriate developmental environment, based on the infant's age and status and individual needs. (Pineda et al 2017 [A]; Symington and Pinelli 2006 [A]; Symington and Pinelli 2002 [A]; McAnulty et al 2010 [B]) [New evidence 2022]	1A

Pain management

6. **It is recommended** that occupational therapists promote the use of non-pharmacological pain management strategies (e.g. skin-to-skin care, facilitated tucking etc.) by all caregivers (parents and practitioners) for pain management during appropriate, planned, painful caregiving procedures. (Axelin et al 2006 [A]; Ferber and Makhoul 2008 [A]; Zargham-Boroujeni et al 2017 [A]; Johnston et al 2011 [A]; Hatfield et al 2020 [B]; Obeidat et al 2009 [B]; Cong et al 2012 [B]; Kostandy et al 2008 [C]) [New recommendation 2022]	1A
7. **It is recommended** that occupational therapists support parent understanding and engagement in appropriate pain management strategies to enable them to provide sensitive support to their infants and promote parent self-efficacy. (Axelin et al (2006) [A]; Franck et al 2011 [A]; Franck et al 2012 [C]; Richardson et al 2020 [C]) [New evidence 2022]	1A
8. **It is recommended** that occupational therapists work with the neonatal team to promote routine assessment of neonatal pain and identification of appropriate pain management strategies. (Gibbins et al 2015 [C]; Orovec et al 2019 [C]) [New evidence 2022]	1C

Skin-to-skin (kangaroo) care

9. **It is recommended** that occupational therapists collaborate with the neonatal team to facilitate parent engagement in skin-to-skin care for high-risk infants to promote pain management, physiological regulation and infant weight gain. (Ludington-Hoe et al 2004 [A]; Vittner et al 2018 [A]; Cunningham et al 2018 [A]; Boo and Jamli 2007 [A]; Cong et al 2009 [A]; Cho et al 2016 [B]; Head 2014 [B]; Bloch-Salisbury et al 2014 [C]; Carbasse et al 2013 [C]; Kostandy et al 2008 [C]) [Amended statement and new evidence 2022]	1A
10. **It is recommended** that occupational therapists collaborate with the neonatal team to facilitate parent engagement in skin-to-skin care for high-risk infants to promote breastmilk feeding, parent wellbeing and parent self-efficacy. (Morelius et al 2015 [A]; Vittner et al 2018 [A]; Mu et al 2020 [A]; Gathwala et al 2008 [A]; Hake-Brooks and Anderson 2008 [A]; Cho et al 2016 [B]; Vittner et al 2019 [B]; Blomqvist et al 2013 [C]) [Amended statement and new evidence 2022]	1A

Touch

11. **It is recommended** that occupational therapists facilitate the provision of positive touch and infant massage* by parents/primary caregivers to decrease infant stress and improve state and physiological regulation. (Asadollahi et al 2016 [B]; Baniasadi and Hosseini 2019 [C]; Kim et al 2017 [C]; Elsagh et al 2019 [D]) [New recommendation 2022]	1B
12. **It is recommended** that occupational therapists facilitate the provision of positive touch and infant massage* by parents to decrease parent anxiety and promote parent mood and parent–infant relationship. (Shoghi et al 2018 [B]; Lotfalipour et al 2019 [C]; Afand et al 2017 [C]; Kim et al 2017 [C]) [New recommendation 2022]	1B

* NB: Please see information in section 5.5.1 regarding the requirement for specialist training/certification to facilitate parent-delivered infant massage with high-risk infants in the neonatal unit setting.

Postural Support

13. **It is recommended** that occupational therapists collaborate with the neonatal team to facilitate individualised postural support recommendations for infants that promote infant motor outcomes, self-regulatory behaviours and prevent respiratory compromise. (Lai et al 2016 [A]; Santos et al 2017 [B]; Kochan et al 2019 [B]; Gouna et al 2013 [C]; Grenier et al 2003 [C]; Liaw et al 2012 [C]; Nakano et al 2010 [C]) [Statement amended and new evidence 2022]	1C
14. **It is recommended** that occupational therapists review the selection and use of neonatal postural support aids for their ability to promote infant motor outcomes, the development of infant postural control and self-regulatory behaviours. (Madlinger-Lewis et al 2015 [B]; Zarem et al 2013 [C]) [Statement amended 2022]	1B
15. **It is recommended** that occupational therapists use a postural support assessment tool to support the education of the neonatal team and promote individualised positioning of high-risk infants in the neonatal unit. (Coughlin et al 2010 [D]) [Statement amended 2022]	1D

Infant feeding

16. **It is recommended** that occupational therapists collaborate with the neonatal team to support parents in reading and responding to infant feeding readiness cues to promote the co-occupation of feeding in the neonatal unit and following transition to home. (Ross and Browne 2013 [B]; Brown and Pridham 2007 [C]; Caretto et al 2000 [C]; Mitha et al 2019 [C]; Maguire et al 2018 [C]; Swift and Scholten 2010 [C]; Ward et al 2000 [C]; Chrupcala et al 2015 [D]; Waitzman et al 2014 [D]) [New evidence and statement amended 2022]	1C
17. **It is recommended** that occupational therapists promote an appropriate environment in the neonatal unit to support parent/infant participation in early feeding experiences. Environmental support factors may include space, seating, privacy, sensory environment and NICU culture. (Flacking and Dykes 2013 [C]; Pickler et al 2013 [C])	1C

Parent engagement

18. **It is recommended** that occupational therapists work with parents of high-risk infants to support parenting roles and relationships, and to provide sensitive and appropriate parent engagement in the infant's care in the neonatal unit. (Ding et al 2019 [A]; Gibbs et al 2015 [A]; O'Brien et al 2018 [A]; Bäcke et al 2020 [C]; Dudek-Shriber 2004 [C]; Gibbs et al 2016 [C]; Pineda et al 2018 [C]; Gustafson et al 2016 [C]; Ganadaki and Magill-Evans 2003 [D]; Price and Miner 2009 [D]; Skene et al 2019 [D]) [New evidence 2022]	1A
19. **It is recommended** that occupational therapists facilitate the development of co-occupations related to activities of daily living (including, but not limited to, feeding, bathing, nappy changing, dressing and play activities of daily living) with preterm and low birthweight infants to ensure sensitive and appropriate caregiving and promote occupational performance of infants and parents. (Chiarello et al 2006 [C]; Kadlec et al 2005 [C]; Winston 2015 [D]) [Statement amended 2022]	1C
20. **It is recommended** that occupational therapists working with families of high-risk infants build a positive therapeutic collaboration with parents to enhance parental learning about their infant both during and following the transition to home. (Aydon et al 2018 [B]; Fucile et al 2020 [C]; Harrison et al 2007 [C]; Ingram et al 2016 [C]) [New evidence 2022]	1B
21. **It is suggested** that occupational therapists explore both traditional and innovative methods (e.g. video-conferencing) of supporting families post-discharge from the neonatal unit as a means of promoting parent confidence and competence in caring for their infant following the transition to home. (Gund et al 2013 [C])	2C

Parent support

22. **It is recommended** that occupational therapists support engagement in parenting occupations in the neonatal unit and following discharge (including, but not limited to, reading infant cues, guided participation in care, skin-to-skin, positive touch and holding) to promote decreased parent stress and positive improvements in parent–infant relationship and self-efficacy. (Evans et al 2014 [A]; Månsson et al 2019 [A]; Matricardi et al 2013 [B]; Melnyk et al 2006 [A]; Milgrom et al 2019 [A]; O'Brien et al 2018 [A]; Thomson et al 2020 [A]; White-Traut et al 2013 [A]; Zelkowitz et al 2011 [A]; Bäcke et al 2020 [C]; Nassef et al 2020 [C]; Suarez et al 2018 [C]) [New evidence 2022]	1A

23. **It is recommended** that occupational therapists employ parent-focused interventions that incorporate parental attunement in order to reduce the psychosocial impact of delivering a high-risk infant, foster sensitive nurturing behaviour and promote the cognitive development of preterm infants. (Als et al 2003 [A]; Benzies et al 2013 [A]; Melnyk et al 2001 [A]; Nordhov et al 2010 [A]; Askary Kachoosangy et al 2020 [B]; Kraljevic and Warnock 2013 [B]) [New evidence 2022]	1A
24. **It is suggested** that occupational therapists engage parents in brief activity-based interventions during their infant's admission to the neonatal unit and that this can have a short-term effect in lowering parent anxiety. (Dür et al 2018 [B]; Mouradian et al 2013 [C]) [New evidence 2022]	2B
25. **It is recommended** that occupational therapists consider the use of e-health interventions (e.g. web-based platforms, mobile apps, video-conferencing etc.) to support parent engagement, particularly when parent presence may be interrupted. (Dol et al 2017 [A]) [New recommendation 2022]	1A
26. **It is recommended** that occupational therapists employ the use of parent-focused psychosocial interventions to decrease parent stress and anxiety and promote parent coping, confidence and early parent–infant relationships. (Kasparian et al 2019 [A]; Gramszlo et al 2020 [B]; Petteys and Adoumie 2018 [B]) [New recommendation 2022]	1A

Identifying developmental concerns

27. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to cognitive performance and social interaction, to support the development of the infant's occupations, with referral to early intervention services as indicated. (Maitra et al 2014 [A]; Magill-Evans et al 2002 [C]; Pineda et al 2015 [C]; Sajaniemi et al 2001 [C])	1A
28. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to functional motor skills, to support the development of the infant's occupations, with referral to early intervention services as indicated. (Maitra et al 2014 [A]; Bigsby et al 2011 [B]; Watkins et al 2014 [C]; Fewell and Claussen 2000 [C])	1A

29. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to sensory processing difficulties, to support the development of the infant's occupations, with referral for early intervention services as indicated. (Bröring et al 2017 [A]; Witt Mitchell et al 2015 [B]; Crozier et al 2016 [C]) [New evidence 2022]	1A

Early intervention

30. **It is recommended** that occupational therapists provide early developmental intervention programmes for preterm infants to promote improved cognitive performance through the preschool years. (Orton et al 2009 [A]; Spittle et al 2015 [A]; Spittle et al 2007 [A])	1A
31. **It is recommended** that occupational therapists provide home-based early intervention programmes for infants born <30 weeks' gestation in the first year of life as this may result in decreasing parent anxiety. (Spencer-Smith et al 2012 [A])	1A
32. **It is recommended** that occupational therapists facilitate individualised functional motor interventions for high-risk infants and young children to promote engagement in early occupations such as play, exploration and participating in personal care (activities of daily living). (Lekskulchai and Cole 2001 [A]; Hughes et al 2016 [A]; Duncan et al 2020 [B]) [New evidence 2022]	1A
33. **It is recommended** that occupational therapists incorporate home routine/occupation-based approaches in early intervention programmes for children at risk for developmental delay as a means of promoting occupational performance. (Hwang et al 2013 [B])	1B
34. **It is recommended** that occupational therapists be routinely referred preterm infants with the following co-morbidities: septicaemia, extremely low birthweight (ELBW), chronic lung disease, periventricular leukomalacia (PVL) or intraventricular haemorrhage (IVH) (grade III–IV), for early intervention. (Hintz et al 2008 [C])	1C
35. **It is recommended** that occupational therapists working in early intervention settings with high-risk infants consider key elements when building a therapeutic collaboration with parents – promoting effective collaboration amongst multiagency providers, supporting family social/emotional needs in addition to infant developmental concerns, and consistency of service provision. (Ideishi et al 2010 [D])	1D

It is additionally recommended that occupational therapists use the audit tool that is available to support this guideline (see Section 7) to undertake audit against the above recommendations. Recommendations for which there is a transdisciplinary component may be usefully audited jointly with other members of the multidisciplinary team. Likewise, the occupational therapist may be involved in audits related to other frameworks, such as the Bliss Baby Charter Standards and audit tool (Bliss 2020).

1 Background

The Neonatal Intensive Care Services Review Group (Department of Health 2003) found that as the effectiveness of neonatal care has become apparent, due to a number of factors such as increasing technical advancements, demand for this highly specialist care has grown. Intensive care is now being offered to infants of significantly earlier gestational age at birth. Indeed, research has shown a 14% improvement in the survival rates of those born at 25–31 weeks' gestation from 1997 to 2011 (Marlow 2015). In light of these trends, the British Association of Perinatal Medicine published a new guidance framework to support clinical decision making regarding the care of infants born between 22 and 27 weeks' gestational age (BAPM 2019).

Neonatal occupational therapy has also commensurately evolved during this time to provide sensitive, individualised and family-centred developmental interventions to support this increasingly complex clinical group. The presentation of infants in the days, weeks and months following preterm or high-risk term delivery and subsequent developmental concerns provide the strong impetus for provision of occupational therapy in early intervention and prevention.

A further emerging element that is relevant to neonatal occupational therapy is the impact of parental factors and subsequent involvement in child development. Developmentally supportive care interventions provided by occupational therapists in neonatal units, and early intervention/prevention models used in follow up, are embedded within a family-centred care approach. Understanding parental mental health outcomes following preterm birth is important due to the potentially negative effects on a child's health and development. Associated concerns relate to parental impairment in ability to recognise/respond to infant cues that have been shown to demonstrate an impact on development of synchronicity in interaction, the provision of fewer learning opportunities, an increase in child behaviour/emotional regulation issues, and an impact on language and cognitive development (Treyvaud 2014, Treyvaud et al 2011).

This guideline focuses on evidence to inform occupational therapy in neonatal services and early intervention in the UK.

1.1 Practice requirement for the guideline

Occupational therapists make a significant contribution to the care of preterm and high-risk infants, as their professional remit uniquely provides a focus on the developing occupations of infancy and childhood, including for those infants receiving care in a neonatal unit. This approach includes occupational performance components such as adaptation to the environment, systems theory and the enablement of occupational roles (e.g. parenting in neonatal care). Enabling occupational engagement of parents and infants includes an understanding of body functions and structures (e.g. sensory processing, cognition, emotional regulation, motor development etc.). This guideline is intended to support occupational therapists in these roles.

1.2 Topic identification process

In 2013, the Neonatal Occupational Therapy Clinical Forum (under the auspices of the Royal College of Occupational Therapists' Specialist Section – Children, Young People and

Families) was established. This built on a previous model of a special interest group of occupational therapists working in neonatal services. In both its previous and current iterations, there has been a long-standing identification of the need for the development of a UK-specific guideline for occupational therapy practice in this specialist area.

The reasons underpinning the need for the development of the guideline include:

- The need for a resource that is specific and sensitive to the UK occupational therapy context. Although guidelines relating to skills and competencies for occupational therapists working in neonatal care have been published by the American Occupational Therapy Association (AOTA) since 1993, there are some key differences in the scope of occupational therapy practice between the two nations.

- As neonatal occupational therapy is a specialised area of practice, occupational therapists can find themselves in a position of being asked to commence service delivery to neonatal services without specific experience. As a therapist may not have a background of paediatric occupational therapy service delivery, there is a significant increase in skills and knowledge required to be able to practise effectively and safely in this area. The development of a guideline will ensure that all therapists (experienced and otherwise) who are providing neonatal services are doing so informed by the best available evidence.

- The guideline covers occupational therapy from birth to 2 years' corrected age – this supports the key window of neuroplasticity and ensures that early intervention models are considered that support prevention or reduction of impact on later educational, social and economic areas of performance.

The National Institute for Health and Care Excellence (NICE) has accredited the process used by the Royal College of Occupational Therapists to produce its practice guidelines. Accreditation is valid for five years from January 2018 and is applicable to guidance produced using the processes described in the *Practice guideline development manual*, fourth edition (RCOT 2020).

A guideline project proposal was developed by the Neonatal Occupational Therapy Clinical Forum and this was subsequently approved by the Royal College of Occupational Therapists' Practice Publications Group in December 2015.

1.3 National context

Over 100,000 infants in the UK were admitted to a neonatal unit in 2016 (National Data Analysis Unit 2016). Many of these infants are surviving birth at younger gestational ages than in the past.

A large body of research highlights the impact of the increase in survival of infants born prematurely and provides clarity around the range of neurodevelopmental issues with which preterm infants commonly present. These include cognitive impairment, cerebral palsy, impairments in motor planning, visuo-spatial, sensorimotor and attention functions, behavioural issues, increased incidence of autism spectrum disorders, neurosensory impairment, cognitive impairment and delayed social-emotional competence (Johnson et al 2009, Marlow et al 2007, Larroque et al 2008, Delobel-Ayoub et al 2009, Johnson et al 2014, Guy et al 2015, Hee Chung et al 2020, Laverty et al 2021).

Additionally, infants born at term who experience complications such as hypoxic ischaemic encephalopathy will need ongoing developmental support and monitoring. Nearly half of these infants will experience adverse outcomes, such as cerebral palsy or motor/cognitive impairment (Pin et al 2009, Magai et al 2020). Furthermore, children who do not show signs of severe developmental outcomes initially may later experience subtle issues, such as learning difficulties (Pin et al 2009).

Neonatal care is divided into three types: special care (Level I), high-dependency care (Level II) and neonatal intensive care (Level III). Special care is for infants who need additional care, while high-dependency care is for infants requiring highly-skilled staff, though with a lower nurse-to-patient ratio than a neonatal intensive care unit. Neonatal intensive care is for infants who are 'most unwell or unstable and have the greatest needs in relation to staff skills and staff to patient ratios' (British Association of Perinatal Medicine [BAPM] 2011, p3). It provides the full range of medical neonatal care. Finally, transitional care is where the mother cares for the infant with support from a midwife or healthcare professional who may not have specialist neonatal training (BAPM 2011).

1.4 Context of service delivery

Across the nations[1] of the UK, government documents have outlined principles or frameworks to support the delivery of neonatal services. These include:

- *Toolkit for high-quality neonatal services* (Department of Health 2009)
- *Neonatal care in Scotland: a quality framework* (Scottish Government 2013)
- *The best start: a five year forward plan for maternity and neonatal care in Scotland* (Scottish Government 2017)
- *All Wales neonatal standards, third edition* (NHS Wales 2017).

These documents provide a structure for the delivery of neonatal services, including elements of geographical organisation, facility requirements, staffing recommendations, education and training standards, and clinical governance. They also emphasise the importance of placing infants and families at the core of service delivery with the implementation of a family-centred care approach.

NHS England commissioned the Neonatal Critical Care Review (NCCR) in 2018–19 to address the issues highlighted in the national maternity review and the Five Year Forward View for maternity care (NHS England 2016). The Royal College of Occupational Therapists Specialist Section for Children, Young People and Families (Neonatal Forum) was involved in this project, which included the development of occupational therapy staffing recommendations for neonatal units which contributed evidence to the review (RCOT 2018).

The commitment of the NCCR, as part of a wider government strategy outlined in the NHS Long Term Plan (2019), was to halve the number of neonatal deaths by 2025 by improving neonatal outcomes. In order to enable this, the NCCR identified seven key actions required to transform neonatal services and to implement a new vision for neonatal care across England (NHS England 2019). The implementation plan for the NCCR includes action points to address shortfalls in the neonatal workforce, including developing strategies to ensure equitable and recommended provision of allied health services for all infants and families receiving neonatal care.

In Scotland, the Best Start Maternity and Neonatal Review (2017) also recommended ways to reorganise and improve neonatal services to ensure they are family-centred and responsive to the needs of the individual. The recommendations cover provision of services, and workforce planning and needs.

The third edition of the Welsh neonatal standards (2017) similarly emphasises family-centred care, and aims to improve shared learning among the neonatal workforce and retention of expertise.

Additionally, the British Association of Perinatal Medicine has published 'Optimal arrangements for neonatal intensive care units in the UK including guidance on their medical staffing' (BAPM 2021a). This contains a statement about the need for neonatal units to deliver the required level of therapy and allied health professional supports, including access to specialist occupational therapists. Service delivery will also be influenced by national commissioning specifications (NHS England 2015) and local policies and guidance.

What all have in common is the idea that the family is the central element of care provision, and occupational therapists, as part of multidisciplinary teams (MDTs), work towards that aim. To further this aim, some UK nations are adopting Family Integrated Care (FICare) (BAPM 2021b), which aims to place parents centrally in the care of their infant in the neonatal setting. Occupational therapists are uniquely placed to ensure that the occupations so critical to parents' and infants' identities are not lost in the neonatal unit, helping to keep the family at the centre of care.

Note

1 No similar document could be found for Northern Ireland.

2 The occupational therapy role

Occupational therapy is centred on promoting health and wellbeing through enabling engagement and participation in everyday occupations. It uses a framework which focuses on the relationship between the person, their environment and the occupations that they need or would like to do. Occupational therapists bring to the multidisciplinary neonatal team knowledge of infant neurobehavioural and neuromotor development and an understanding of the impact of the physical/sensory/psychosocial environment on infant development and family-centred care. When working with high-risk infants, occupational therapists promote optimal development of the child and work with families to support them to engage and participate in their role as parents/carers. Inclusion of neonatal therapists (occupational therapists, physiotherapists and speech and language therapists) is an essential component of a comprehensive preventive model of developmental care (Craig and Smith 2020).

RCOT published the first national guidelines that provided detailed recommendations for occupational therapy practice in neonatal care specific to the UK context in 2017.

Recognition of occupational therapy as a critical contribution to the neonatal unit is also acknowledged in the joint position statement from the Canadian Association of Neonatal Nurses, Canadian Association of Perinatal and Women's Health Nurses, National Association of Neonatal Nurses (NANN) and Council of International Neonatal Nurses (COINN) on developmental neuroprotective care service design and delivery in the NICU (Milette et al 2017a, Milette et al 2017b).

As discussed previously, provision of occupational therapy was also listed by the Neonatal Critical Care Review (NCCR) 2019 as part of the key theme 'developing the expert neonatal workforce'. The document recognised that neonatal units could no longer operate with only medical and nursing teams but required contribution from an essential group of allied health professionals.

In the UK, occupational therapists provide services to high-risk infants across a range of neonatal services, including neonatal units (levels 1–3), transitional care units, maternity units, paediatric intensive care units (PICUs), acute paediatric inpatient wards and within early intervention services in the community.

Occupational therapy services within neonatal settings are focused on supporting the development of the high-risk infant and their family. Occupational therapists work collaboratively with parents of high-risk infants to facilitate the infant's and parents' occupational roles, support the parent–infant relationship and ensure a successful transition from hospital to home and community. In addition, occupational therapists contribute to the provision and promotion of developmentally supportive care of high-risk infants. This approach serves to minimise the potential for harm of the neonatal unit environment on the infant's developing brain and to support their growth and development in order to promote early engagement with their parents, including co-occupations such as nurturing touch and the introduction of feeding, bathing and handling. As the infant is discharged from the unit and grows older, ongoing intervention and/or guidance provide continued opportunities to support the development of infant occupations around self-care, learning and play. Through educating parents on strategies to support and engage their infant with appropriate sensory

and motor experiences, occupational therapists can provide building blocks for developmental progression and parent–infant interaction.

The breadth of practice and degree of specialised care required in the neonatal unit require the occupational therapist to demonstrate advanced knowledge and skills in neonatal care to provide complex interventions to critically ill neonates and their families (Vergara et al 2006). These include knowledge of emerging competencies in infant occupation, child development and medical knowledge, family-centred practice and developmental approaches (Vergara et al 2006).

Finally, although this guideline is focused on the provision of neonatal occupational therapy services, it is imperative that occupational therapists work collaboratively with other professionals in the neonatal unit and follow-up settings to promote the best outcomes for infants and their families, which support their mutual participation in and enjoyment of occupations that align with their family values and priorities.

3 Objective of the guideline

The guideline objective is:

To provide evidence-based recommendations to inform occupational therapy in neonatal services and early intervention in the UK.

Neonatal occupational therapy services aim to provide sensitive, individualised and family-centred developmentally supportive interventions to support high-risk infants and their families. The use of an occupation-centred approach to practice enables occupational therapists not only to support the high-risk infant but also to ensure that parents of high-risk infants are enabled to become sensitively involved in the care of their infant and to develop parenting occupations.

The guideline addresses occupational therapy intervention for high-risk infants and their families at any point from birth until the infant reaches 2 years' corrected age. Although the guideline focuses on this group of high-risk infants, it is recognised that where resources are available, occupational therapy services may benefit all infants admitted to a neonatal unit (e.g. those born moderate to late preterm). The objective serves to support the clinical reasoning of occupational therapists in regard to:

- providing and promoting individualised care of high-risk infants and supporting their engagement with relevant occupations (e.g. sleeping, feeding, exploring)
- working with individual families to negotiate their meaning of parenting and parent– infant co-occupations
- providing sensitive opportunities for parenting occupations to create more ordinary and positive experiences for parents and their infants within the neonatal unit.

The application of the guideline will also inform the delivery of evidence-based services.

This guideline should be used in conjunction with the current versions of the following professional practice documents (knowledge of and adherence to these standards is assumed):

- *Standards of conduct, performance and ethics* (Health and Care Professions Council [HCPC] 2016).
- *Standards of proficiency – occupational therapists* (HCPC 2013).
- *Professional standards for occupational therapy practice, conduct and ethics* (RCOT 2021).

Occupational therapists should also be familiar with their relevant country-specific policy documents and performance measures, and cognisant of the following guideline:

- *Developmental follow up of children and young people born pre-term: Quality Standard 169* (NICE 2018).

Finally, occupational therapists should have awareness of other documents related to the provision of neonatal occupational therapy services:

- *Bliss Baby Charter* (Bliss 2020).
- *Working together to safeguard children* (HM Government 2018).
- *Optimal arrangements for neonatal intensive care units in the UK including guidance on their medical staffing: a framework for practice* (BAPM 2021a)
- *Service standards for hospitals providing neonatal care* (BAPM 2010).
- *Toolkit for high-quality neonatal services* (Department of Health 2009).
- *Implementing the recommendations of the neonatal critical care transformation review* (NHS England 2019).
- *Occupational therapy's role in the neonatal intensive care unit* (American Occupational Therapy Association 2018).
- *Specialized knowledge and skills for occupational therapy practice in the neonatal intensive care unit* (Vergara et al 2006).

Occupational therapists must only 'provide a service that is within [their] professional competence, appropriate to the needs of those who access the service, and within the range of activities defined by [their] professional role' (RCOT 2021, p7). This guideline should be used in conjunction with the therapist's clinical expertise and, as such, the clinician is ultimately responsible for the interpretation of the evidence-based recommendations in the context of their specific circumstances and the infants' and families' individual needs.

4 Guideline scope

4.1 Clinical question

The key question identified in the scope for this guideline was:

What is the evidence to support occupational therapy in neonatal services and in early intervention?

4.1.1 Key outcomes

The Guideline Development Group members identified key outcomes as a result of occupational therapy intervention(s), from their knowledge of the evidence base and clinical expertise. These include the following:

- Earlier discharge from an initial inpatient admission.
- Fewer readmissions.
- Improved parent wellbeing (e.g. increased confidence, improved self-efficacy, reduced anxiety).
- Increased opportunities for parent engagement on the neonatal unit.
- Promotion of parent–infant relationship.
- Fewer missed appointments in early intervention services due to the collaborative partnerships formed between parents and therapists.
- Earlier identification of emerging developmental concerns and implementation of appropriate early intervention services or referral to relevant specialist services.

The heterogeneity of the population means that it can be difficult to identify the specific outcomes that will be the most important to an individual infant or parents. A person-centred perspective underpins occupational therapy practice, and intervention must be compatible with the families' preferred outcomes or, where appropriate, in their best interests.

It is recognised that the evaluation of outcomes is complex and will be influenced by a variety of factors. The ability to quantify the achieved outcomes will depend on the personalised goals set with each individual family (for example, increased time at the infant's bedside, increased engagement in skin-to-skin care).

4.1.2 Key areas for inclusion in the guideline scope

Occupational therapy interventions will be determined based on the individual needs of the infant and family, including (though not limited to) gestational age at birth, medical status and appropriate levels of support for family engagement. Using an occupation-centred approach, specific interventions to be considered for inclusion are:

- The provision and promotion of infant and family developmentally supportive care of high-risk infants.

- Assessment and guidance regarding the infant's neurobehavioural state – this includes key working with parents in understanding the infant's cues and preparing parents for interaction with their infants. By helping to sensitise parents to their infant's behavioural cues, appropriate interactions and levels of stimulation can be enabled.

- Guidance of positioning of infants to support neurobehavioural regulation (for example, habituation to external stimuli, motor responses and consolidation of and transition between sleep/wake states). The provision of postural support helps to promote infants' self-regulation of their autonomic and motor systems and reduces the risk of muscle imbalance.

- Adaptation of environment to modify sensory input, minimise stress and facilitate interactive behaviours.

- Follow-up assessment and/or intervention for infants as defined by national guidelines in accordance with additional risk factors. Specific local guidelines may also inform identification of gestation and birthweight indicators for formal follow-up services.

- Supporting individual families to negotiate their meaning of parenting and facilitating parent and infant co-occupations.

- Identifying caregiving activities that are meaningful to parents and foster opportunities for engagement.

- Provision of psychosocial support for parents, including reassurance, encouragement and information.

- Provision of opportunities for parents to attain a physical connection with their infant (e.g. comfort holding, skin-to-skin holding), and to work to increase opportunities for parents to participate in physical touch of their infant as the infant's stability increases.

- Work to influence the multidisciplinary team to promote an NICU culture that supports and values parental engagement in care, including the promotion of staff communication styles that are empowering and enabling of parents.

- Contribute to discharge planning in a cohesive and collaborative manner.

- Work collaboratively with the multidisciplinary team in the identification of safeguarding concerns.

- The provision of intervention and/or guidance to support the development of infant occupations around self-care, learning and play.

- Developmental activities with guidance on suitable toys, play opportunities and activities for developmental stage and individual needs, increasing caregivers' awareness of developmental needs and ability to respond appropriately to those needs within everyday home/community-based routines.

- Early identification and implementation of interventions for infants identified at risk of significant neurodevelopmental sequelae which may lead to motor, sensory and cognitive dysfunction. Deficits in these domains may result in suboptimal participation in and

development of occupations, including participation in play opportunities, exploring the environment, early learning and developing independence in self-care occupations.

- Provision of infant equipment, particularly to promote safe and optimal participation in infant occupations such as play, bathing, feeding/eating, mutual engagement in family routines and activities.

4.1.3 Key areas for exclusion from the guideline scope

Some areas of occupational therapy practice overlap with those of other therapy service providers in the neonatal setting. Other aspects fall into areas outside the remit of occupational therapy practice in the UK and require additional skill and expertise. Therefore, the following areas are being excluded from the scope of this guideline:

- mechanical aspects of feeding (including formalised swallowing assessments and dysphagia management)
- supporting elements of volume/flow/latch for breastfeeding
- management of chest clearances and other respiratory support
- management of musculoskeletal abnormalities of the lower limb
- assessment/treatment of torticollis.

4.2 Target population

The guideline covers the predominant presentations of infants who receive services from occupational therapists working in neonatal services. A collective term of 'high-risk infants' has been used to describe this population, which includes all infants born preterm, high-risk infants born at term (e.g. infants with neonatal hypoxic ischaemic encephalopathy, neonatal abstinence syndrome, congenital conditions or having undergone complex surgical procedures), infants receiving palliative care, and their parents. In alignment with the British Association of Perinatal Medicine and the Neonatal Toolkit, the guideline also encompasses occupational therapy provision for these infants from birth to 2 years' corrected age to ensure promotion of relevant support and intervention during the key window for neuroplasticity and the developing parent–infant relationship.

4.3 Target audience

The principal audience for this guideline is occupational therapists working in neonatal and affiliated services, including paediatric settings.

This guideline is applicable to occupational therapy staff delivering services to parents and infants in a range of settings, including neonatal units, maternity units, transitional care units, paediatric intensive care units and children's wards (for older infants previously treated within a neonatal unit). Additionally, the guideline includes recommendations to inform practice in the provision of follow-up and early intervention services for high-risk infants. These settings may include hospital clinics and outpatient settings, child development services, early-years services, home-based services, private clinics, and early education providers.

This guideline is also relevant to a wider audience:

- Occupational therapists who provide information and education to other clinical providers such as health visitors and general practitioners.
- Members of the multidisciplinary team: to provide a greater understanding of the role of the occupational therapist in neonatal settings and early intervention. This will promote closer working between disciplines (including nursing, medical and other multidisciplinary team staff), with the potential for improved outcomes for infants and their parents.
- Managers, network leads and commissioners: to provide evidence of the role of occupational therapy, and thus inform business planning and commissioning of services.
- Education providers: as an educational tool, orientating individuals to an evidence-based resource to support the occupational role in neonatal and early intervention services.
- Students: as a resource to inform their learning.
- Researchers: to provide information on the latest evidence and to identify areas for further research.
- Parents: to provide information to enable them to be more informed about the occupational therapy process in neonatal and early intervention services.

5 Recommendations and supporting evidence

The recommendations developed by the Guideline Development Group and Guideline Review Group are underpinned by the evidence available to date which supports the delivery of occupational therapy neonatal services and early intervention in the UK. Details of the guideline methodology, including the development process and the literature search strategy, are set out in Sections 9 and 10.

Synthesis of the evidence resulted in the emergence of recommendations for occupational therapy services that promote the performance of infant occupations, parent occupations and parent–infant co-occupations. These recommendations have been categorised in the following core areas:

- Occupation-based assessment
- Developmentally supportive care
- Pain management
- Skin-to-skin (kangaroo) care
- Touch
- Postural support
- Infant feeding
- Parent engagement
- Parent support
- Identifying developmental concerns
- Early intervention

These themes cut across the desired outcomes identified (see Section 4.1), but while the recommendation statements have been set out within these categories, it is essential to recognise that there are overlaps. Individual recommendations should not be considered in isolation but in the wider context.

The strength of the recommendations is identified via a scoring of 1 (strong) or 2 (conditional), and the quality of the supporting evidence via a grading on a scale of A (high quality) to D (very low quality). A recommendation grading considers the consistency in the direction of the outcomes from the individual items of evidence used to support that recommendation (see Section 10.4 for more detail).

Thirty-three of the 35 recommendations were agreed by the Guideline Review Group as being strong; that is, most infants and/or parents would want to, or should, receive the course of intervention or action stated. The other two recommendations were conditional; that is, most infants and/or parents would want the intervention, but not all would, with the risks and benefits being more closely balanced. Additional details on individual studies (for example, on study design, methodological limitations, recruitment numbers and statistical significance) can be accessed in the evidence tables (Appendix 2). Where side effects have been reported in the supporting evidence, this has been noted in the text.

Outcomes desired, risks, generalisability and social determinants of health associated with the recommendations are outlined in Section 5.12. Potential financial and organisational barriers are discussed in Section 7.2.

This guideline focuses specifically on the delivery of occupational therapy services as defined in the scope and does not set out to compare occupational therapy services with other interventions or professional scope of practice in the neonatal setting. Given the degree of overlap in relation to the delivery of developmentally supportive care interventions in the neonatal setting, occupational therapists should, however, be aware of the scope of their interventions which may overlap with services provided by neonatal physiotherapists, speech and language therapists and neonatal nurses. Often, the planning of how developmentally supportive care services are delivered is managed on a unit by unit basis, based on the availability of professional input within the multidisciplinary team. While the recommendations for practice outlined below all fit within the core scope of occupational therapy practice in the UK, occupational therapists need to recognise the scope of practice of other members of the neonatal multidisciplinary team and collaborate to provide a consistent family-centred approach to neonatal care delivery (Barbosa 2013).

Recommendations are based on a synthesis of the best available evidence (sourced from English language publications). It should, therefore, be noted that the guideline is not able to reflect the full range of possible interventions. It does, however, support those for which evidence was available, and where there was agreement among the Guideline Review Group on the inclusion of the intervention within the core scope of neonatal occupational therapy practice.

The guideline recommendations are presented under the core categories that reflect the areas of assessment and intervention that an occupational therapist may provide in the neonatal unit and in follow-up services after discharge from hospital (e.g. early intervention services). Assessment refers to the approach that an occupational therapist uses to evaluate an infant's strengths and vulnerabilities to help direct where support can be provided to facilitate engagement in infant occupations. Interventions refer to those activities that occupational therapists provide to support infants and their families to engage in mutually satisfying parent–infant co-occupations.

5.1 Occupation-based assessment

5.1.1 Introduction

To best support high-risk infants and their families, occupational therapists should provide appropriate, safe and sensitive assessment. Underpinning the approach to assessment is the consideration of an individual infant's early engagement patterns during routine caregiving and other elements associated with occupational performance. Inherent in an occupation-based assessment approach is the consideration of family values, concerns and priorities, and the physical and social environment of the infant (Vergara and Bigsby 2004).

Identification of an infant's strengths and vulnerabilities as they experience caregiving interactions in the neonatal unit allows the occupational therapist to work collaboratively with the infant's parents and the multidisciplinary team. Together they can identify and implement appropriate strategies to support the infant's development and their participation in parent–infant co-occupations. In recognising that some high-risk infants are at increased risk for developmental sequelae, appropriate use of assessment also ensures that occupational therapists provide timely guidance and identify those infants and families who would benefit from more structured support and ongoing service delivery. Further, NICE guidance recommends that post-discharge, infants who were born before 30 weeks' gestation or with specified neurological co-morbidities receive enhanced developmental surveillance, including therapy input, until 2 years of age (NICE 2018).

Occupational therapy approaches are underpinned by systems theory in which the successful performance of daily activities and tasks is recognised as being influenced by a constant interplay between the person and their surrounding environment. Occupational therapy training programmes equip therapists to conduct detailed analysis of the person and environmental factors that contribute to performance. In relation to high-risk infants, occupational therapists bring an approach to assessment that considers the potential impact of the physical and social environment on an infant's ability to manage their neurobehavioural self-regulation and subsequently identify strategies that appropriately support the infant's strengths and vulnerabilities.

The completion of an occupation-based assessment allows in-depth analysis of the activities and underlying capacities that the infant must master to support their participation in specific caregiving activities or family engagement. This analysis can be used to identify and recommend specific interventions that enable their occupational performance.

Occupation-based assessment

1. **It is recommended** that occupational therapists safely and appropriately assess the neurobehavioural status of the high-risk infant, in order to plan/deliver developmentally supportive care. (Als et al 2003 [A]; Pineda et al 2020 [B]; El-Dib et al 2011 [C]; Allinson et al 2017 [D]) [New evidence 2022]	1A
2. **It is recommended** that occupational therapists assess neurobehavioural and neurodevelopmental status to provide guidance and identify infants appropriate for developmental follow up following discharge. (Craciunoiu and Holsti 2017 [A]; Bartlett 2003 [C]; Sucharew et al 2012 [C]; Crowle et al 2015 [D]; Liu et al 2010 [D]) [New evidence 2022]	1A
3. **It is recommended** that occupational therapists liaise with community teams and assess neurodevelopmental status for high-risk infants in the first two years of life to provide guidance and implement early intervention services where indicated. (Liu et al 2010 [D])	1D

5.1.1 Recommendation 1: Assessment of neurobehavioural status to support the delivery of developmentally supportive care

Als et al (2003) conducted a randomised controlled trial which included 92 infants drawn from three neonatal units in the United States. The study aimed to test the effectiveness of individualised developmental care across multiple sites that involved NICU settings with different nursing-assignment patterns (primary and conventional care) and that served transported and inborn infant populations. Infants in the experimental group received the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) intervention, with the infants in the control group receiving standard care.

Each infant in the experimental group received structured NIDCAP observations on a weekly basis. These structured observations provided detailed and sensitive assessment of the infant's strengths and vulnerabilities. The observations were then used to provide recommendations for strategies to promote the infant's stability and competence. Infants receiving the NIDCAP structured observations and interventions demonstrated significantly improved medical outcomes at 2 weeks' corrected age in relation to feeding outcomes, length of hospital admission, lower incidences of necrotising enterocolitis, and better growth (weight, weight gain, height, and head circumference). From a developmental perspective, infants who had received the NIDCAP approach also demonstrated significantly improved outcomes.

Pineda et al (2020) conducted a prospective longitudinal study of 88 very preterm infants born at <30 weeks' estimated gestational age (EGA) to determine the relationship between infant medical factors and early neurobehaviour, and the relationship between infant neurobehaviour at 30 weeks postmenstrual age (PMA) and neurobehaviour at term-equivalent age. Infants in the study had neurobehaviour assessed at 30 weeks PMA using the Premie-Neuro and at term-equivalent age using the NICU Network Neurobehavioral Scale (NNNS) and the Hammersmith Neonatal Neurological Evaluation (HNNE).

The authors identified that lower Premie-Neuro scores at 30 weeks PMA were related to a range of factors including earlier gestational age at birth, the presence of patent ductus arteriosus (PDA), cerebral injury, and prolonged exposure to oxygen therapy, endotracheal intubation and total parenteral nutrition. When key factors were considered in a multivariate model (EGA, PDA and days of intubation), lower Premie-Neuro scores at 30 weeks PMA were independently related to lower total HNNE scores at term age and worse outcomes on the NNNS with poorer quality of movement, and more stress, asymmetry, excitability and suboptimal reflexes. The results for the study indicate a need for accurate neurobehavioural assessments of infants, particularly those born very preterm with co-morbid medical complications.

El-Dib et al (2011) conducted a cohort study with 67 infants who were recruited from a single neonatal unit in the United States. This study aimed to identify a correlation between an infant's performance on the NICU Network Neurobehavioral Scale (NNNS) at term-equivalent age and their developmental outcomes at 18 months (as assessed by the Bayley Scales of Infant Development). The NNNS is a non-invasive neonatal assessment tool which assesses the full range of infant neurobehavioural performance, including neurological integrity, behavioural functioning and infant stress signs (Lester et al 2014). The study findings supported an association between concerns identified on the NNNS and neurodevelopmental delay at 18 months' corrected age. Neurodevelopmental delay was associated with poorer behavioural regulation, non-optimal reflexes, increased hypertonicity

and an increased need for infant handling strategies to support the infant to maintain an alert state.

Allinson et al (2017) conducted a prospective observational study with 34 infants born at <30 weeks' gestational age to compare the physiological stress responses when undergoing clustered nursing care with standardised neurobehavioural assessments. Three assessment tools were used – the General Movements Assessment (GM), the Premie-Neuro Assessment (PN) and the Hammersmith Neonatal Neurological Examination (HNNE), which were administered weekly from birth until 32 weeks postmenstrual age. Physiological data of heart rate and oxygen saturation was recorded. The results showed that compared with clustered nursing care, heart rate was lower and oxygen saturation was higher during standardised neurobehavioural assessments. They were also associated with a reduced odds ratio of tachycardia, heart rate instability and oxygen desaturation. The authors concluded that standardised neurobehavioural assessments were associated with less physiological stress than clustered nursing cares in infants aged 29–32 weeks PMA and therefore possible to be used without causing undue physiological disturbance in medically stable infants.

Evidence overview

Occupational therapists can make a significant contribution to the delivery of developmentally supportive care in the neonatal unit. A key component of the delivery of developmental care is appropriate assessment of the infant's neurobehavioural status throughout the neonatal unit admission to support the implementation of an individualised plan that changes as the infant matures. The evidence supports the use of sensitive assessments that reflect the infant's fragility, and uses structured infant observation. The evidence supporting this recommendation consists of one well-structured randomised controlled trial and three cohort studies, with an overall high level of evidence grading.

5.1.2 Recommendation 2: Assessment of infant neurobehaviour and neurodevelopment to provide guidance and identification for developmental follow up

Craciunoiu and Holsti (2017) conducted a systematic review of the validity of neurobehavioural assessments administered to preterm infants before term-equivalent age to predict long-term neurobehavioural outcome. The review incorporated five assessments used in 11 studies. These were the Neonatal Behavioural Assessment Scale (NBAS), the Test of Infant Motor Performance (TIMP), the General Movements Assessment (GM), the Neurobehavioural Assessment of the Preterm Infant (NAPI) and the Neonatal Oral Motor Assessment Scale (NOMAS). The included studies underwent methodological quality assessment. The review identified that the predictive validity of the neurobehavioural assessments was variable in relation to later neurodevelopmental outcome. Two measures, the TIMP and the GM, were identified as having promising predictive validity with moderate to high specificity. The others reported low to moderate associations with later neurodevelopmental outcome.

Sucharew et al (2012) conducted a cohort study which aimed to evaluate the impact of low-level prenatal and early-childhood exposure to a variety of environmental factors on child health and development. The study included 355 infants, with detailed assessment conducted with the NNNS at 5 weeks of age, and the Bayley Scales of Infant Development-II at 12, 24 and 36 months. The study identified that infants who were considered to have a hypotonic profile at 5 weeks of age were more likely to have difficulties with motor performance in early childhood.

A cohort study by **Liu et al (2010)** aimed to ascertain whether the NNNS was a predictor of negative medical and behavioural findings from 1 month to 4.5 years of age. The study included 1,248 infants in the United States who were recruited as part of the Maternal Lifestyle Study. Infants were assessed with the NNNS at 1 month of age, and with other developmental and IQ assessments administered when the children were 4, 8, 12, 24, 36, 48 and 52 months of age. The study findings confirmed that infants who were of high risk (due to prenatal drug exposure, gestational age and low birthweight, and neurological concerns) demonstrated discrete profiles on the NNNS that were significantly associated with issues related to behavioural problems, school readiness and IQ through to 4.5 years of age.

Crowle et al (2015) conducted a cohort study which aimed to explore whether the General Movements Assessment could identify common risk profiles in high-risk infants who had undergone major surgery. The study incorporated 170 infants from a single unit in Australia. The most common profile seen in this group of infants was poor repertoire (47%). Eight per cent of infants were identified with cramped synchronised movements, which have the highest indication for identification of cerebral palsy.

Bartlett (2003) conducted a cohort study with 60 infants in Canada which aimed to use the Alberta Infant Motor Scale (AIMS) to measure and describe the patterns of motor development in 8-month-old preterm infants. The study identified that the AIMS could be used to confirm infants with neurological abnormalities, but did not have ongoing utility with this population in terms of monitoring future motor development. There is the ability to use the AIMS as a discriminative assessment for infants considered to have normal or suspect motor development, and it had ongoing utility as a monitoring tool for infants demonstrating suspect motor development.

Evidence overview

A key component of the delivery of neonatal occupational therapy is appropriate assessment of the infant's neurobehavioural status throughout the neonatal unit admission, and neurodevelopmental status in preparing for transition to home. Occupational therapists must select assessments with appropriate sensitivity and specificity. Supporting an infant's and family's transition to home via the provision of individualised guidance is essential, as is ensuring appropriate follow-up services for children identified as at risk of developmental sequelae. The evidence supports the use of appropriate assessments that reflect the infant's age and status, to gain a comprehensive understanding of the infant's strengths and vulnerabilities in order to provide ongoing support and management (Craciunoiu and Holstii 2017, Sucharew et al 2012, Crowle et al 2015, Liu et al 2010, Bartlett 2003). The evidence supporting this recommendation consists of one systematic review considered high-level evidence and four cohort studies – two of which were considered as having low levels of evidence, and two very low levels of evidence.

5.1.3 Recommendation 3: Assessment of neurodevelopmental status through the first two years of life

Liu et al (2010) conducted a cohort study which aimed to ascertain whether the NNNS was a predictor of negative medical and behavioural findings from 1 month to 4.5 years of age. The study included 1,248 infants in the United States who were recruited as part of the Maternal Lifestyle Study. This was a longitudinal study of children considered at risk due to prenatal drug exposure and prematurity. Infants were assessed with the NNNS at 1 month of age, with other developmental and IQ assessments administered when the children were 4, 8, 12, 24, 36, 48 and 52 months of age. The study findings confirmed that infants who

were of high risk (due to prenatal drug exposure, low gestational age and birthweight, and neurological concerns) demonstrated discrete profiles on the NNNS that were significantly associated with issues related to behavioural problems, school readiness and IQ through to 4.5 years of age.

Evidence overview

High-risk infants are at increased risk for neurodevelopmental and functional sequelae that can impact their participation in infant and child occupations. Occupational therapists can provide a significant contribution to monitoring the developmental outcomes of these infants to ensure early identification of concerns and appropriate referral to early intervention services where indicated. The evidence supports the use of neurodevelopmental assessments in identifying children at later risk of experiencing difficulties across a range of occupational domains (Liu et al 2010). The evidence supporting this recommendation consists of one cohort study of very low-level evidence.

A range of relevant assessments was reviewed in the evidence appraisal process; however, the papers identified do not reflect the full range of assessment tools available for use with this population. The selection of specific assessment tools is a matter of clinical judgement and includes issues such as availability and training. Examples of assessments used within neonatal occupational therapy services are provided in Appendix 4.

5.2 Developmentally supportive care

5.2.1 Introduction

Infant and family-centred developmentally supportive care (European Foundation for the Care of Newborn Infants) is a term that refers to the use of strategies that are 'derived from neurodevelopmental, environmental and human sciences to improve the potential of infants who are disadvantaged by premature birth or adverse perinatal events' (Warren and Bond 2010, p14). For ease, the term developmentally supportive care will be used throughout this document to refer to a range of models and approaches. The aim of developmentally supportive care models is to alter the focus of neonatal care from the traditional task-oriented or procedure-oriented approach to a focus on processes and relationships, including the increased involvement of families (Westrup 2007, Oostlander et al 2019).

The term developmentally supportive care comprises a range of specific interventions, or intervention programmes, such as NIDCAP (Lawhon 2002, Als 2008), Family Integrated Care (O'Brien et al 2013) and the Mother–Infant Transaction Program (Rauh et al 1990). Although programmes designed to deliver developmentally supportive care differ in components and approach, they employ a range of common attributes (National Association of Neonatal Nurses 2001). These include:

- individualised, flexible care based on identification of and responsiveness to each infant's competencies, vulnerabilities and emerging abilities
- providing developmentally supportive individualised environments
- supporting the development of parent–infant relationships
- recognising the rights of parents within a family-centred care model
- collaborative practice by all practitioners

- consistency of caregivers to promote continuity of care.

As developmentally supportive care programmes have evolved, research has been undertaken to understand their efficacy in improving the developmental outcomes of high-risk infants. Although there is some inconsistency in the research findings, the potential benefits of developmentally supportive care have emerged, with many neonatal units now adopting this approach (Vergara and Bigsby 2004).

Occupational therapists are well placed to both implement and act as a resource for the multidisciplinary team in relation to the delivery of developmentally supportive care as a result of their approach of considering the interplay of human, occupation/activity and environmental factors on performance. Sensitive assessment of the impact of the caregiving environment on the infant can support the selection of appropriate strategies that match the infant's individual capacities, and minimise stress and trauma.

Developmentally supportive care	
4. **It is recommended** that developmentally supportive care principles are implemented for high-risk infants admitted to neonatal units to enhance short-term health and developmental outcomes. (Als et al 2003 [A]; McAnulty et al 2009 [A]; Symington and Pinelli 2006 [A]; Legendre et al 2011 [B]; McAnulty et al 2010 [B]; Oostlander et al 2019 [B]; Soleimani et al 2020 [B]; Wallin and Eriksson 2009 [B]) [New evidence 2022]	1A
5. **It is recommended** that occupational therapists promote an appropriate developmental environment, based on the infant's age and status and individual needs. (Pineda et al 2017 [A]; Symington and Pinelli 2006 [A]; Symington and Pinelli 2002 [A]; McAnulty et al 2010 [B]) [New evidence 2022]	1A

5.2.2 Recommendation 4: Developmentally supportive care to improve health and developmental outcomes

Wallin and Eriksson (2009) conducted a systematic review which aimed to assess the effects of individualised developmentally supportive care on the psychomotor development, neurological status, medical outcomes and parent perceptions of preterm infants. The review incorporated 12 papers drawn from the reporting of six randomised controlled trials that had been conducted in the United States and Sweden using NIDCAP as the experimental intervention compared with traditional care. Approximately 250 infants were included across the six studies.

The collated results of the studies demonstrated a trend for positive findings for the infants receiving the NIDCAP intervention in relation to motor and cognitive development. Five studies reported an improvement in psychomotor development as measured by the Assessment of Preterm Infant Behavior (APIB) at 2 weeks' corrected age. Three of the studies reported improved cognitive outcomes at 9 months to 2 years as measured by the Bayley Scales of Infant Development (I and II) (Mental Development Index). The authors did report that the variability in how infant outcomes were reported across the study posed difficulties in conducting more complex meta-analysis of the findings. A common

methodological concern across the studies was small sample sizes, yielding low statistical power.

McAnulty et al (2009) conducted a randomised controlled trial which aimed to assess the effect of NIDCAP on medical outcome and on behavioural and electrophysiological function. The study included 107 infants who were recruited from one neonatal unit in the United States. Infants in the experimental group received the NIDCAP intervention, with the infants in the control group receiving standard care. The outcomes for all infants in the study were measured at 2 weeks' corrected age and 9 months' corrected age using a variety of outcome measures.

The study identified that the infants who had received NIDCAP demonstrated a significant reduction in major medical morbidities of prematurity, and significant improvements in their overall neurodevelopmental function at 2 weeks' corrected age. At 9 months' corrected age, the infants who had received NIDCAP were still demonstrating significant improvements over those in the control group in relation to their neurobehavioural functioning.

The randomised controlled trial conducted by **Als et al (2003)** included 92 infants drawn from three neonatal units in the United States. The study aimed to test the effectiveness of individualised developmental care for the first time across multiple sites that involved NICU settings with different nursing-assignment patterns (primary and conventional care) and that served transported and inborn infant populations. Infants in the experimental group received the NIDCAP intervention, with the infants in the control group receiving standard care. Structured NIDCAP observations were completed on a weekly basis, which provided recommendations for strategies to promote the infant's stability and competence. Outcomes related to medical status, developmental status and parent functioning were measured at 2 weeks' corrected age.

Infants receiving the NIDCAP intervention demonstrated significantly improved medical outcomes at 2 weeks' corrected age in relation to feeding outcomes, length of hospital admission, lower incidences of necrotising enterocolitis, and better growth (weight, weight gain, height and head circumference). From a developmental perspective, infants who had received the NIDCAP approach also demonstrated significantly improved outcomes. They showed better regulation in their autonomic and motor systems, and improved self-regulation. Finally, in relation to parent functioning, parents of infants supported by the NIDCAP approach also perceived their infants as having improved regulation. They also experienced enhancements in their parental competence, with a corresponding reduction in stress experiences.

Symington and Pinelli (2006) conducted a Cochrane systematic review, incorporating 36 studies involving 2,220 infant participants. The aim of the review was to identify whether developmental care interventions reduced neurodevelopmental delay, poor weight gain, length of hospital stay, length of mechanical ventilation, physiological stress and other clinically relevant adverse outcomes in preterm infants. These papers included a range of developmental care interventions grouped on the basis of: i) positioning; ii) clustering of nursery care activities; iii) modification of external stimuli; and iv) individualised developmental care interventions. The included studies were conducted in a range of international settings including the UK, Switzerland, Sweden, Israel, Canada and the Netherlands, with the majority undertaken in the United States.

The overall results from the review indicated that developmental care interventions demonstrated some effect in enhancing neurodevelopmental outcomes and identified

limited benefits in relation to improved family outcome. This review experienced some difficulties with the collation of the study findings due to variability of results, which may have been linked to small sample sizes in the individual studies and variations in outcome measurement. The review also highlighted that none of the studies had considered the cost of the interventions and personnel.

A second randomised controlled trial undertaken by **McAnulty et al (2010)** aimed to explore the continuity of NIDCAP effectiveness into school age by testing the predictability of brain function in the infant period with school-age neuropsychological results. The study involved 22 children, 11 of whom had received NIDCAP interventions during an admission to a neonatal unit in the United States, and 11 who had received standard care. The children were assessed at 8 years' corrected age. This study included only a small sample of children, which may impact the precision of the results, but children who had received NIDCAP interventions during infancy demonstrated significantly better spatial visualisation and mental control. Electroencephalogram assessment also demonstrated improved cortical connectivity, corroborating the neuropsychological findings with the development of neural pathways.

Legendre et al (2011) conducted a systematic review that aimed to document the short-term medical and developmental effects of the NIDCAP programme. The review included 15 papers that were drawn from 13 randomised controlled trials and two cohort studies.

Findings across the studies in relation to short-term medical outcomes were mixed. There was greater consistency in reporting improvements in infant behavioural organisation for infants who received a NIDCAP approach, specifically in relation to state regulation, attention and motor control. Only two of the included studies focused on sleep outcomes – the first indicated that infants receiving NIDCAP demonstrated improved self-regulation and fewer sleep–wake cycles, with the second demonstrating improved wake periods by 34 weeks postmenstrual age. Due to the variability in the reporting in the original studies, only descriptive analysis of the findings was possible. Most of these studies focused on short-term outcomes (at 2 weeks' corrected age); the evidence for the effectiveness on longer-term developmental outcomes remains weak.

A systematic review by **Soleimani et al (2020)** reviewed the effects of developmental care in the NICU on the mental and motor development of preterm infants. The authors used a broader definition of developmental care than the specific NIDCAP-focused definition in the studies summarised above. Developmental care was included if it consisted of environmental stress controls, individualised approaches such as NIDCAP, integration of parents and behavioural techniques on neonates. Twenty-one randomised controlled trials were included in the review. The results indicated that developmental care interventions could have neuro-protective effects on the mental and motor development of infants, particularly when assessed at 12 months of age. However, the heterogeneity of the included studies meant that an overall estimate of effect could not be generated. Included studies were also drawn from a period of 46 years, with the authors noting the potential impact of the significant changes during this time in the management and care of neonates.

Finally, **Oostlander et al (2019)** conducted a scoping review to identify the non-pharmacological interventions currently used in the treatment of infants with neonatal abstinence syndrome (NAS) that fall within the scope of occupational therapy. The review included 45 studies of both quantitative and qualitative methodologies. Developmentally

supportive interventions that were identified as being effective in terms of supporting infants with NAS included postural support, wrapping, gentle/paced handling, maintaining temperature stability, environmental modifications (including light, sound and smell), non-nutritive sucking, vestibular and tactile input. Interventions supporting the mother–infant dyad were also noted to be important with attributes of education/support, rooming-in and the promotion of skin-to-skin contact. As a scoping review, data aggregation and re-analysis of the individual studies were not completed, and the authors note that most of the studies included were considered low levels of evidence.

Evidence overview

The evidence supporting the positive impact of developmentally supportive care interventions for high-risk infants is drawn from four systematic reviews, three randomised controlled trials and one scoping review. It is recognised that due to factors that influence the design and methods when conducting studies in the NICU, there are weaknesses in the methods used within the primary studies and limitations in the transferability of the findings. The delivery of developmentally supportive care can lead to benefits for the infant and family, including improved infant neurodevelopmental and neurobehavioural outcomes, improved short-term growth and feeding development, decreased respiratory support, decreased length and cost of hospital stay, and improved parent confidence and stress levels.

No specific risks were reported in any of the studies for the infants receiving developmental care interventions.

The search strategy only identified evidence predominantly relating to evaluation of NIDCAP interventions. Occupational therapists should recognise that there is a range of developmentally supportive care programmes and approaches that may also be used to enhance the care provided to high-risk infants and their families. Such programmes and approaches include, but are not limited to, the Infant Behavioural Assessment and Intervention programme (IBIAP) (Hedlund 1998), Family Integrated Care (O'Brien et al 2013), the Mother–Infant Transaction Program (MITP) (Rauh et al 1990) and Family Nurture Intervention (Welch et al 2012).

5.2.3 Recommendation 5: Developmentally supportive care implications for the neonatal environment

Symington and Pinelli (2006, 2002) conducted a Cochrane systematic review, incorporating 36 studies involving 2,220 infant participants. The aim of the review was to identify whether developmental care interventions reduced neurodevelopmental delay, poor weight gain, length of hospital stay, length of mechanical ventilation, physiological stress and other clinically relevant adverse outcomes in preterm infants. One of the components of developmental care interventions considered in the review was the provision of individualised interventions based on the infant's age and status.

The creation of an appropriate developmental environment, based on each individual infant's requirements, was shown to reduce the likelihood of moderate to severe chronic lung disease and necrotising enterocolitis. Positive neurodevelopmental outcomes for infants have also been demonstrated in relation to cognitive and learning function when assessed at 9–12 months of age, though there is some inconsistency across study findings. One study, which included a longer follow-up period, identified retained benefits in relation to behaviour and movement skills at 5 years of age.

McAnulty et al's (2010) randomised controlled trial (as detailed previously), which aimed to explore the continuity of NIDCAP effectiveness into school age, captured some potential long-term benefits for infants who receive appropriate individualised interventions to their care environment. These children demonstrated better perceptual and cognitive function than those who had received standard care. Additionally, for the infants who had undergone routine neurobehavioural assessments during the neonatal period (as part of the provision of individualised developmental care), these measures were more predictive of neuropsychological function at 8 years than more commonly used demographic or medical outcome variables.

Pineda et al (2017) conducted an integrative review of sensory-based interventions used with very preterm infants in the NICU to improve infant and parent outcomes. The review included 88 studies which used a quantifiable sensory-based intervention in the NICU with preterm infants born ≤32 weeks' gestation that measured infant- and parent-related outcomes. A variety of sensory modalities was included in the original papers, including tactile, auditory, visual, kinaesthetic, gustatory/olfactory and multimodal interventions. Due to the heterogeneity of the included studies, the findings could not be combined quantitatively. The authors also noted that the significant variability in sensory exposures, outcomes, dosages and timing of sensory interventions makes it challenging to ascertain a cohesive understanding of appropriate sensory exposures across postmenstrual age (PMA). The review identified little evidence to suggest improved long-term outcomes from sensory interventions; however, there was some evidence to support the use of kangaroo care, music and language exposure, and multimodal interventions starting at 25–28 weeks PMA.

Evidence overview

The evidence supporting the positive impact of developmental care interventions, particularly when focusing on the creation of an individualised, developmentally appropriate environment for high-risk infants, is of high and moderate quality. It is recognised that due to factors that influence the design and methods when conducting studies in the NICU, there are limitations in the transferability of the findings. The delivery of these interventions can lead to benefits for the infant, including improved infant neurodevelopmental outcomes and decreased risk for moderate to severe respiratory and gastrointestinal complications of prematurity.

Because of occupational therapy's focus on how the environment impacts parent and infant roles, it is an important aspect of the occupational therapist's role to recommend how to create a supportive environment that promotes and supports infant occupational participation (e.g. supporting sleep, facilitating parent–infant interaction). Managing the neonatal unit sensory environment is a key part of individualised developmental care interventions.

No specific risks were reported in any of the studies for the infants receiving developmental care interventions.

5.3 Pain management

5.3.1 Introduction

Being born prematurely or sick and needing admission to a neonatal unit unfortunately exposes infants to painful procedures that are required as part of their caregiving. Procedures that cause pain and/or stress to high-risk infants include blood sampling,

endotracheal intubation, tracheal suctioning, orogastric or nasogastric tube insertion and retinopathy of prematurity examinations (Coughlin 2014).

The neuroanatomical and neuroendocrine mechanisms that facilitate the transmission of a painful stimulus are functional in the developing foetus at 20–22 weeks' gestation (Bellieni 2012). Infants born preterm may also experience non-noxious stimuli (e.g. nappy change) as painful or stressful due to heightened sensitivity, and broader neuronal receptors. The presence of hypersensitivity is complicated by delayed maturation of the descending pain pathways in the infant, which help to modulate the pain experience (Bhutta and Anand 2002).

Studies have demonstrated that preterm infants may have prolonged experiences of pain (Bhutta and Anand 2002). On average, a preterm infant in the neonatal unit experiences 14 painful procedures every day (Johnston et al 2014). Repetitive painful procedures have a dramatic effect on brain architecture (Brummelte et al 2012). Repetitive pain results in structural and functional reorganisation of the central nervous system (Williams and Lascelles 2020). Furthermore, when pain is prolonged and unmanaged or undermanaged, infants may experience decreased energy expenditure and enter a state of passivity, decreased heart and respiratory rate, and decreased oxygen consumption (American Academy of Pediatrics [AAP] et al 2006). Infants who experience repeated exposure to painful stimuli may develop a hyperalgesia or increased responsiveness to the experience (AAP et al 2006).

Neonatal unit staff try to manage infants' experiences of pain with pharmacological and non-pharmacological pain management strategies. Occupational therapists can also contribute to infant pain management using two approaches. Firstly, through detailed and sensitive observation of an infant's neurobehavioural regulation during painful and caregiving procedures, an occupational therapist can support identification of the infant's stress or pain signs. These can be shared with parents and other caregiving staff to increase awareness of the infant's response to stress/pain and when they need additional support. Secondly, occupational therapists can work with parents to identify strategies that parents could/may use in the non-pharmacological management of their infant's pain.

Pain management

6. **It is recommended** that occupational therapists promote the use of non-pharmacological pain management strategies (e.g. skin-to-skin care, facilitated tucking etc.) by all caregivers (parents and practitioners) for pain management during appropriate, planned, painful caregiving procedures. (Axelin et al 2006 [A]; Ferber and Makhoul 2008 [A]; Zargham-Boroujeni et al 2017 [A]; Johnston et al 2011 [A]; Hatfield et al 2020 [B]; Obeidat et al 2009 [B]; Cong et al 2012 [B]; Kostandy et al 2008 [C]) [New evidence 2022]	1A
7. **It is recommended** that occupational therapists support parent understanding and engagement in appropriate pain management strategies to enable them to provide sensitive support to their infants and promote parent self-efficacy. (Axelin et al (2006) [A]; Franck et al 2011 [A]; Franck et al 2012 [C]; Richardson et al 2020 [C]) [New evidence 2022]	1A

8. **It is recommended** that occupational therapists work with the neonatal team to promote routine assessment of neonatal pain and identification of appropriate pain management strategies. 1C

(Gibbins et al 2015 [C]; Orovec et al 2019 [C])
[New evidence 2022]

5.3.2 Recommendation 6: The provision of non-pharmacological pain management strategies by parents and practitioners

Axelin et al (2006) conducted a randomised crossover trial which aimed to examine the effectiveness of facilitated tucking in pain management during endotracheal suctioning of preterm infants. Facilitated tucking involves the parents using their hands to support the infant in a flexed position in the incubator during caregiving procedures. The study included 20 infants from a single neonatal unit in Finland. The infants' pain experience was assessed using an infant pain profile, and heart rate and oxygen saturation recording. The study findings indicated that the use of facilitated tucking alleviated behavioural pain signs in preterm infants. Additionally, 95% of parents involved in the study reported that they preferred being able to participate in their infant's pain management approach compared with passive observation.

Ferber and Makhoul (2008) conducted a randomised controlled trial which aimed to examine the effect of skin-to-skin care on preterm infants who were undergoing a painful procedure. The study included 30 infants, between 28 and 34 weeks' gestation, who were recruited from a single NICU in Israel. Infants were assessed during blood sampling (via heel lance) and observed in either skin-to-skin care with their mother or in a standard care setting in the incubator. The study identified that infants' pain reactions were different across the study conditions. When held in skin-to-skin care, there was a noted decrease in the infant's motor disorganisation and extension movements, and an increase in attention signs. Additionally, significant neurobehavioural changes were sustained in the follow-up period (20 minutes) after the blood sampling in comparison with incubator care.

In a double-blinded randomised clinical trial, **Zargham-Boroujeni et al (2017)** compared the effectiveness of breastfeeding, massage and standard care as non-pharmacological pain management techniques to support infants undergoing venipuncture. Seventy-five infants who were >34 weeks postmenstrual age underwent venipuncture either after 3 minutes of active sucking at the mother's breast or after 3 minutes of efflorage (stroking) massage over the planned venipuncture site. For infants in the control group, no non-pharmacological pain measures were used. The study identified that both the breastfeeding and massage interventions resulted in significantly reduced pain scores when compared with the control group, with the massage intervention showing the greatest efficacy.

Johnston et al (2011) conducted a randomised crossover trial which aimed to evaluate skin-to-skin care provided by mothers and fathers to reduce pain from heel lance (blood sampling). The study involved 75 preterm infants (28–36 weeks' gestation) and was conducted in three neonatal units in Canada. Skin-to-skin care was provided for the infants for at least 15 minutes prior to the blood test, maintained during the procedure, and then continued for a minimum of 15 minutes afterwards. The study demonstrated that the infant pain scores were lower for infants receiving skin-to-skin care from either their mothers or fathers when compared with procedures conducted when the infants were in the incubator. There were different results between mothers and fathers during skin-to-skin care, with mothers identified as providing marginally more comfort for their infants.

Hatfield et al (2020) conducted a systematic review of behavioural and environmental interventions for procedural pain management in preterm infants. The review included 14 randomised controlled trials on infants <37 weeks postmenstrual age hospitalised in a neonatal unit, which assessed the effectiveness of pain management interventions using a reliable neonatal pain scale to assess infant behavioural pain response. The individual studies considered pain management in response to a range of painful diagnostic and treatment procedures that infants experienced during standard care in the neonatal unit (e.g. heel lance, venipuncture, endotracheal suctioning, laser treatment for ROP). The interventions received by the infants included swaddling, acupuncture, kangaroo care, oral dextrose, oral sucrose, non-nutritive sucking, facilitated tucking and breastmilk. The evidence synthesis indicated that across age groups, facilitated tucking was the most frequent intervention and demonstrated decreases in behavioural and physiological pain responses, alone and with other pain management interventions. Oral sucrose and kangaroo care also showed promising effects, though potential bias was noted in each study. No significant adverse effects were associated with any of the interventions included in the review. The authors conclude that behavioural and environmental interventions can be used with preterm infants to significantly mitigate biobehavioural pain responses associated with painful procedures. However, they note that the overall low-quality evidence and the heterogeneity of the studies limits confidence in the findings.

Obeidat et al (2009) conducted a descriptive systematic review which aimed to determine the efficacy of facilitated tucking as a non-pharmacological pain management strategy in preterm infants. The review included five papers, all of which used crossover study designs. The age of the infants in the original studies ranged from 23 to 36 weeks, and incorporated between 12 and 40 infants. The pain procedures most explored were blood sampling (heel lance) and endotracheal suctioning. While no meta-analysis of the findings was completed, some consistencies in infant outcomes were observed. All studies demonstrated a lower infant heart rate during the painful procedure with facilitated tucking, and three of four also demonstrated improved oxygen saturation levels. Infant behavioural responses to pain were noted to decrease with facilitated tucking in three of four studies.

In a randomised controlled trial conducted by **Cong et al (2012)**, the length of the provision of skin-to-skin care (30 minutes versus 15 minutes) prior to and then throughout a blood sampling procedure was compared to incubator care. The study findings indicated that heart rate decreases occurred in a small group of infants across all conditions, though this occurred more frequently during incubator care. Heart rate changes were noted to differ significantly across the three groups, occurring more frequently in the incubator care group. Infants who received 15 or 30 minutes of skin-to-skin care prior to the procedure were also noted to spend more time in quiet sleep.

Kostandy et al (2008) conducted a pilot crossover trial with ten infants born at 30–32 weeks' gestation to explore the effect of skin-to-skin care on crying responses to pain. Infants were evaluated in either skin-to-skin care with their mother, or in an incubator during a blood sampling procedure (heel stick). Infant crying time was significantly less when the procedure was conducted during skin-to-skin care.

Evidence overview

The evidence supporting the provision of a range of environmental and behavioural pain management interventions is growing. There is strong evidence for intervention such as parental skin-to-skin care as a means of pain management, and the provision of facilitated tucking during planned painful procedures. Although the sample sizes in the individual studies are small, they demonstrate consistent findings in supporting infant outcomes relating to neurobehavioural/state regulation during painful caregiving procedures. This recommendation is supported by four randomised controlled trials, two crossover trials and two systematic reviews.

Occupational therapists can promote the use of non-pharmacological pain management strategies, especially as a component of promoting parent engagement during planned painful procedures.

5.3.3 Recommendation 7: Parent engagement in neonatal pain management

Franck et al (2011) conducted a randomised controlled trial which aimed to demonstrate feasibility and estimate the effect of an intervention to increase parental involvement in infant pain management in the NICU on parents' stress and post-discharge parenting competence and confidence. The study included 169 parents recruited from four neonatal units across the UK. All parents received an information booklet about generic neonatal unit care. Parents in the experimental arm also received a booklet that presented evidence-based information about pain and comforting infants in the neonatal unit. They were also supported by two sessions with a nurse who demonstrated how to use the techniques described in the booklet. The study findings showed no differences between the two groups in relation to their experience of stress. However, parents in the experimental arm demonstrated significantly more satisfaction with pain information, being supported to read infant cues and comforting techniques, and preference for involvement in painful procedures.

In a conjoint qualitative study, **Franck et al (2012)** aimed to understand parents' perceptions and feelings of having participated in the trial, and refine the understanding of parental experience of involvement in infant pain management. Parents' perceptions were gathered via open text responses to the Parent Attitudes about Neonatal Pain survey. The findings demonstrated that parents expressed strong preferences for more information about all aspects of infant pain management, including improved timing of information provision, and facilitated opportunities for involvement. Parents desired increased sensitivity and consistency in relation to infant caregiving, with increased use of specific pain-relieving interventions by neonatal unit staff. Parent involvement in pain management for their infants was also influenced by contextual factors such as the parents' own emotional state and the communication and support received from neonatal unit staff.

Axelin et al (2006) conducted a randomised crossover trial which aimed to examine the effectiveness of facilitated tucking in pain management during endotracheal suctioning of preterm infants. In addition to exploring infant pain responses, the study authors sought to understand parents' experiences of being involved in pain management strategies. The study included 20 infants from a single neonatal unit in Finland. Ninety-five per cent of parents involved in the study reported that they preferred being able to participate in their infant's pain management approach compared with passive observation.

In a scoping review, **Richardson et al (2020)** explored and mapped the current evidence on parent-targeted educational interventions about infant pain, delivered throughout the

perinatal period. Nine studies were incorporated in the review: four RCTs, one cross-sectional survey, one quasi-experimental study, two qualitative studies and one mixed-methods study. All of the educational interventions included information about infant pain management strategies, with specified interventions including breastfeeding, skin-to-skin contact, facilitated tucking, sucrose, topical anaesthetic, non-nutritive sucking, holding, and deep breathing/distraction. The methods of education delivery included written components (e.g. booklets and fact sheets), video components and multimodal approaches (incorporating a mix of written, video, verbal discussion, pictorial information and role-playing). The findings of the review indicated that few studies addressed parent-targeted educational interventions on infant pain and management strategies. Of those that did, interventions were typically multimodal and delivered either in person or passively. The educational interventions appeared to improve parental knowledge and self-efficacy or increased involvement in pain management activities.

Evidence overview

There is strong evidence that parents who have received education and facilitation in how to support their infant during painful procedures feel more confident in their parental role, and overall satisfaction with the care they received (Franck et al 2012, Franck et al 2011). Parents also reported preferring engagement in pain management as an alternative to observing care (Thoyre 2007). This recommendation is supported by two randomised controlled trials, one qualitative study and one scoping review.

In facilitating opportunities for the development of parenting occupations, occupational therapists can promote parent engagement in supporting their infant during painful caregiving procedures.

5.3.4 Recommendation 8: Assessment of neonatal pain

Gibbins et al (2015) conducted a mixed-methods study which aimed to understand how healthcare professionals assessed and managed procedural pain for preterm infants. The study included 59 neonatal staff of varying disciplines drawn from four neonatal units in Canada. Staff perceptions were collected via individual or focus group interviews and by completion of a brief survey. The study served to identify that pain in extremely preterm infants is complex, unpredictable, and challenging to assess and manage. There was strong agreement on the experiences of pain of vulnerable infants and the importance of identifying appropriate pain management strategies in neonatal care. Participants suggested the need for easily accessible and flexible training and education on pain assessment for this high-risk population, to ensure consistency and continuity of care.

Orovec et al (2019) conducted a retrospective secondary analysis of data, collected as part of a larger randomised controlled trial, on a cohort of 242 medically stable preterm infants admitted to a level 3 neonatal unit. This analysis was focused on reporting data about neonatal pain exposure, pain management, and pain assessment and documentation to identify which factors were associated with increased use of pain-relieving interventions. Pain-related procedures were differentiated as tissue-breaking (e.g. heel lance) and non-tissue-breaking (e.g. nasogastric tube insertion). Infant pain was assessed using the Premature Infant Pain Profile (PIPP). The study findings (specific to the use of pain assessment tools) were that the PIPP was used with 56.6% of tissue-breaking procedures and 12.2% of non-tissue-breaking procedures. Overall, 32.6% of procedures had a documented pain score. Further, the authors identified that almost all infants with a documented pain score undergoing procedures received a pain-relieving intervention, thereby supporting the importance of consistent pain assessment and documentation practices for neonatal patients.

Evidence overview

In acknowledging that neonatal care exposes the high-risk infant to painful procedures, the implementation of appropriate pharmacological and non-pharmacological pain management for infants is imperative. This involves routine assessment of infant pain behaviours in order to plan and provide individualised developmentally supportive care. An association has been indicated between the formal assessment of infant pain and the use of pain-relieving measures (Orovec et al 2019). Occupational therapists can promote the use of infant pain assessment tools as linked with their sensitive assessment of infant neurobehavioural regulation and stress cues. It has been demonstrated that neonatal practitioners recognise the complex issues in managing infant pain, including the challenges in ensuring appropriate pain assessment (Gibbins et al 2015). This recommendation is supported by one retrospective secondary analysis of infant data and one low-level qualitatively driven mixed-methods study.

5.4 Skin-to-skin (kangaroo) care

5.4.1 Introduction

The provision of skin-to-skin care is one of the most well-recognised strategies for supporting parent and infant engagement in positive touch experiences. Skin-to-skin care is a popular means of providing warmth, sleep and tactile comfort, as well as opportunities for close parent–infant connection and interaction for preterm infants in the neonatal unit (Vergara and Bigsby 2004). Skin-to-skin care (SSC) in the neonatal unit context has been defined as 'skin-to-skin, chest-to-chest placement of the infant with a parent, ideally the mother' (Ludington-Hoe 2013, p73). SSC is considered a key element of developmentally supportive care as it impacts the following attributes of neonatal care provision: modification of the macro- and micro-environments so that they are calm and soothing for the infant and their family; positioning of the infant in ways that support physiologic stability and motor development; monitoring of all handling of the infant to minimise adverse physiological responses and provide periods of rest; promoting infant self-regulation; promoting state regulation by providing care in tune with the infant's sleep–wake cycles and a quiet soothing environment; and ensuring that all caregiving events are evaluated in terms of infant stress (Als and Gilkerson 1995, Ludington-Hoe 2013). In addition to the physiological and environmental benefits fostered during SSC, occupational therapists promote SSC as a key opportunity for enabling a co-occupation between infants and their parents. The close, nurturing contact provided during SSC supports the development of early infant–parent reciprocal interaction. SSC and other forms of positive touch also provide parents with an opportunity to engage in nurturing occupations that they anticipated during pregnancy, thereby promoting their perceptions of self-efficacy.

Skin-to-skin (kangaroo) care

9. **It is recommended** that occupational therapists collaborate with the neonatal team to facilitate parent engagement in skin-to-skin care for high-risk infants to promote pain management, physiological regulation and infant weight gain. 1A

(Ludington-Hoe et al 2004 [A]; Vittner et al 2018 [A]; Cunningham et al 2018 [A]; Boo and Jamli 2007 [A]; Cong et al 2009 [A]; Cho et al 2016 [B]; Head 2014 [B]; Bloch-Salisbury et al 2014 [C]; Carbasse et al 2013 [C]; Kostandy et al 2008 [C])
[Amended statement and new evidence 2022]

10. **It is recommended** that occupational therapists collaborate with the neonatal team to facilitate parent engagement in skin-to-skin care for high-risk infants to promote breastmilk feeding, parent wellbeing and parent self-efficacy. 1A

(Morelius et al 2015 [A]; Vittner et al 2018 [A]; Mu et al 2020 [A]; Gathwala et al 2008 [A]; Hake-Brooks and Anderson 2008 [A]; Cho et al 2016 [B]; Vittner et al 2019 [B]; Blomqvist et al 2013 [C])
[Amended statement and new evidence 2022]

5.4.2 Recommendation 9: Promoting skin-to-skin care for infant benefit

Ludington-Hoe et al (2004) conducted a randomised controlled trial to assess whether skin-to-skin care improved heart rate, oxygen saturation rate and abdominal skin temperature outcomes. The study involved 24 infants of 33–35 weeks' gestation in a single unit in the United States. Infants in the intervention arm participated in skin-to-skin care with their mother for one inter-feeding interval (ranging from 2.75 to 3.25 hours). The study demonstrated that healthy preterm infants tolerated three hours of skin-to-skin care while maintaining physiological stability. Infants in the experimental arm did not experience any episodes of apnoea, bradycardia or periodic breathing. Regular breathing increased for infants receiving skin-to-skin care compared with those infants receiving standard care.

Vittner et al (2018) conducted a randomised crossover study to examine changes that occur in infant and parent salivary oxytocin and salivary cortisol levels during skin-to-skin contact (SSC) and whether SSC alleviates parental stress and anxiety while supporting mother–father–infant relationships. Twenty-eight stable preterm infants and their parents were enrolled in the study. SSC sessions were 60 minutes in length. Infant cortisol levels decreased significantly during SSC as compared with before and after SSC. Similarly, infant oxytocin levels increased significantly during SSC. The findings indicate that the facilitation of SSC may be an effective intervention to reduce infant stress in the neonatal unit.

Cunningham et al (2018) conducted a systematic review to ascertain if kangaroo care (LC) affects the weights of preterm or low birthweight infants being cared for in the neonatal unit. The review incorporated 17 studies (ten RCTs and seven other quantitative designs) conducted across a variety of geographical settings. Collectively, the studies reported data on 2487 infants. The meta-analysis of the data drawn from the ten RCTs showed a significant difference between the intervention and control groups' data, indicating that KC promoted infant weight gain. A significant weight gain was also noted on four of the seven non-RCT studies. Additionally, six of the studies included in the review indicated a statistically significant increase in the uptake of breastfeeding associated with KC.

Boo and Jamli (2007) conducted a randomised controlled trial to compare weight gain, head growth and breastfeeding rates in very low birthweight infants with or without exposure to short-term skin-to-skin care while in a neonatal unit. The study included 126 infants whose birthweight was <1500 grams, receiving continuous positive airway pressure (CPAP) or inhaled oxygen and tolerating 50% of enteral feedings. The study was conducted in Malaysia. Parents and infants participating in the skin-to-skin intervention were engaged in skin-to-skin care for at least one hour per day. Infants who participated in skin-to-skin care had better average weekly increases in head circumference, and increased breastfeeding rates at discharge.

A randomised crossover trial conducted by **Cong et al (2009)** assessed whether skin-to-skin care assisted in mediating infants' pain responses to heel stick procedures. The study included 14 infants who were born at 30–32 weeks' gestation and were between 2 and 9 days' old. Infants in the experimental group participated in skin-to-skin care for 60 minutes prior to the blood sampling procedure. Infants in the experimental group demonstrated greater autonomic stability at baseline, during and at recovery from the blood sampling than infants receiving standard care in an incubator.

A quasi-experimental study conducted by **Cho et al (2016)** analysed the effects of skin-to-skin care on infant physiological measurements, maternal–infant attachment and maternal stress. The study included 40 infants from a single unit in South Korea who were >33 weeks' gestational age. The study demonstrated no differences between the groups in relation to body temperature and oxygen saturation. For infants receiving skin-to-skin care, their respiration rate was shown to stabilise significantly in comparison with the control group.

Head (2014) conducted a systematic review exploring the effect of skin-to-skin care on the neurodevelopment of preterm infants. The review included ten original studies which explored a variety of effects of skin-to-skin care. In the descriptive analysis, there is limited evidence for the longer-term benefits of skin-to-skin care on neurodevelopmental outcome. However, it was recognised as a positive strategy for promoting neurodevelopment via the mechanisms of: improving early environmental conditions, modifying the infant's experience of stress, promoting organised sleep, and supporting the development of maternal–infant attachment.

Bloch-Salisbury et al (2014) conducted a cohort study to detect any beneficial effect of skin-to-skin care on infants' cardiorespiratory stability. The study included 11 infants of less than 35 weeks' gestational age from one neonatal unit in the United States. Each infant was assessed during an incubator control period. This was followed by a feeding, with skin-to-skin care provided in the following inter-feeding interval. The study findings demonstrated that the respiratory stability of the preterm infant was influenced by sensory perturbations of the caregiver's heartbeat during skin-to-skin care. During skin-to-skin care, infant respiration and apnoea episodes were each directly related to the variability of the caregiver's heart rate. In contrast, during the control period in the incubator, the infant's respiratory instability was directly related to its own heart rate instability.

Carbasse et al (2013) conducted an observational cohort study to assess the safety and effectiveness of skin-to-skin care with vulnerable very preterm infants in the neonatal unit and the impact of respiratory support and infant birthweight in response to skin-to-skin care. The study included 96 infants who were born before 33 weeks' gestation and were recruited from a single neonatal unit in France. The study findings demonstrated that infants receiving skin-to-skin care showed significant increases in oxygen saturation with decreased oxygen requirements, and a decrease in heart rate instability. However, they were noted to have a transient and moderate decrease in axillary temperature following the skin-to-skin transfer. Apnoeic and bradycardic episodes occurred in 13% of skin-to-skin periods, but did not require the need to terminate skin-to-skin care. The authors concluded that skin-to-skin care in the neonatal unit seemed safe and effective even in ventilated very preterm infants.

Finally, **Kostandy et al (2008)** conducted a pilot crossover study which aimed to assess the effect of skin-to-skin care on crying responses to pain. The study was conducted with ten infants born at 30–32 weeks' gestation. Infants were evaluated in either skin-to-skin care

with their mother, or in an incubator during a blood sampling procedure (heel stick). Infant crying time was significantly less when the procedure was conducted during skin-to-skin care.

Evidence overview

The provision of skin-to-skin care for high-risk infants has been heavily researched, with a strong body of evidence demonstrating a range of positive impacts for infants. Skin-to-skin care during a neonatal unit admission has been shown to influence increased breastfeeding, as a way to support infants during painful procedures, to support an infant's physiological regulation, and to promote infant weight gain.

No specific risks were reported in any of the studies for the infants receiving skin-to-skin care.

5.4.3 Recommendation 10: Promoting skin-to-skin care for parent benefit

Morelius et al (2015) conducted a randomised controlled trial to assess the effect of continuous skin-to-skin care on salivary cortisol, parental stress, depression and breastfeeding. The study involved two neonatal units in Sweden and included 37 families. On average, the experimental group participated in 19 hours of skin-to-skin care per day, compared with seven hours for the control group. Those infants who received continuous skin-to-skin care had decreased cortisol reactivity in response to handling, and also improved concordance between mother and infant cortisol levels.

Similarly, **Vittner et al (2018)** conducted a randomised crossover study to examine changes that occur in infant and parent salivary oxytocin and salivary cortisol levels during skin-to-skin contact (SSC) and whether SSC alleviates parental stress and anxiety while supporting mother–father–infant relationships. Twenty-eight stable preterm infants and their parents were enrolled in the study. SSC sessions were 60 minutes in length. In addition to the infant outcomes reported in Section 5.4.2, parent oxytocin levels (both mothers' and fathers') increased significantly during SSC. Parent cortisol levels decreased for both mothers and fathers, though the difference was not significant. Parent anxiety scores were also shown to be significantly related to oxytocin and cortisol levels. Parents with higher oxytocin levels exhibited more synchrony and responsiveness in their infant interactions.

Vittner et al (2019), in a further publication linked to the prospective randomised crossover study with 28 preterm infants outlined above, explored the relationship between parental engagement and salivary oxytocin and cortisol levels for parents who were participating in a skin-to-skin contact (SSC) intervention. Parental engagement was measured using the Parental Risk Evaluation Engagement Model Instrument (PREEMI) prior to hospital discharge. There were moderate to high levels of parental engagement for all participants as measured by the PREEMI. The study results indicated that lower cortisol and higher oxytocin levels in parents, activated during an episode of SSC, were significantly related to parent engagement before discharge.

Mu et al (2020) completed a qualitative systematic review that explored the experiences of parents who had used kangaroo care (KC) for preterm infants in neonatal units. The synthesis included nine qualitative studies, drawn from both English- and Chinese-language publications. Five synthesised findings were identified: a sense of emptiness of the parent's role, barriers in the translation of parental roles in kangaroo care, preparation enhances parental role expectations, kangaroo care enhances parental competency, and encouragement and support from family and friends. It was concluded that through KC,

neonatal staff can help prepare and guide parents, fit parent needs, and help improve both their ability and confidence in the performance of their parental roles.

Gathwala et al (2008) conducted a randomised controlled trial to determine whether the implementation of skin-to-skin care to low birthweight infants would promote mother–infant interaction and attachment. The study included 100 infants with a birthweight of <1800 grams from a single neonatal unit in India. Mothers in the study participated in a structured interview to assess maternal–infant attachment. Infants who received skin-to-skin care experienced a significantly decreased length of stay compared with the control infants. Maternal–infant attachment was reported to be higher in the skin-to-skin group, with mothers being significantly more involved in parenting activities such as bathing and nappy changing. They were also noted to derive more pleasure from their infants.

Hake-Brooks and Anderson (2008) conducted a randomised controlled trial which assessed whether exclusive breastfeeding rates would be higher and of longer duration for infants participating in skin-to-skin care with their mother. The study included 66 mothers and infants who were drawn from two neonatal units in the United States. The study findings indicated that infants and mothers who had participated in skin-to-skin care breastfed for significantly longer than the control dyads (5.08 months compared with 2.05 months). They were also shown to breastfeed more exclusively at discharge, 1.5, 3 and 6 months of age. The average amount of time per day that infants and mothers spent in skin-to-skin care during the neonatal unit admission was 4.47 hours.

As outlined above, a quasi-experimental study conducted by **Cho et al (2016)** analysed the effects of skin-to-skin care on infant physiological measurements, maternal–infant attachment and maternal stress. In addition to the infant outcomes reported above, parents who participated in skin-to-skin care demonstrated higher maternal–infant attachment scores and decreased maternal stress.

Finally, a descriptive study by **Blomqvist et al (2013)** aimed to understand the factors which influenced the time and extent of skin-to-skin care, including who provides it, when and for how much time. The study involved 104 infants from two neonatal units in Sweden. The study identified that both mothers and fathers were involved in the practice of skin-to-skin care. Only three infants experienced skin-to-skin care at birth, with 34 participating in skin-to-skin contact within the first hour and 85 within 24 hours. The remaining infants experienced their first skin-to-skin care between 24 and 72 hours after birth. Skin-to-skin care commenced earlier in infants whose first skin-to-skin contact was with their father. The earlier skin-to-skin care was initiated, the longer the duration that each infant was cared for in skin-to-skin contact per day during their admission.

Evidence overview

The provision of skin-to-skin care for high-risk infants has been heavily researched, with a strong body of evidence demonstrating a range of positive impacts for parents of preterm infants. Skin-to-skin care during a neonatal unit admission has been shown to influence increased confidence in the performance of parental roles, decreased parent stress and anxiety, increased participation in breastfeeding and increased synchrony in early parent–infant relationships. This recommendation is supported by four randomised trials, one quasi-experimental trial, one qualitative meta-synthesis and one descriptive study.

5.5 Touch

5.5.1 Introduction

Positive touch is described as a specially adapted touch for infants who are premature or fragile, and is given according to the individual behavioural and physiological responses of an infant (Warren and Bond 2010). The capacity of the infant born preterm to tolerate and benefit from positive touch is lower at earlier postmenstrual age but improves with increasing maturity. Evidence suggests that gentle human touch may be well tolerated by infants from 27–32 weeks postmenstrual age (Modrein-Talbott et al 2003). Touch has also been identified as an important component of the development of the early parent–infant relationship. Although different from the touch experience anticipated during pregnancy, parents can be supported to engage in skin-to-skin contact in the early weeks of a neonatal admission, with the inclusion of other forms of positive touch and infant massage as the infant matures and is able to tolerate the additional sensory input without being overwhelmed (Aucott et al 2002).

Differing types of neonatal touch and massage have for several decades been documented to have positive effects on both full-term and preterm infants (Abdallah et al 2013). These include gentle human touch, supportive holding, specific types of massage techniques, tactile stimulation and the Yakson method (Chhugani and Sarkar 2014). Trends across these studies suggest that moderate to late preterm infants may receive benefit both physically and developmentally from receiving massage from their parents during the neonatal period, with the parents also receiving benefit in relation to parental wellbeing (Field 2017).

Benefits of the use of neonatal massage are outlined below:

- *Increased weight gain*: increases in infant weight gain as a result of massage provided for 15-minute intervals over a varying number of consecutive days have been demonstrated (Taheri et al 2018; Alvarez et al 2019; Field et al 2008; Diego et al 2007). Similarly, there is moderate evidence that neonatal massage results in improved digestion and increased elimination of waste products (Choi et al 2016; Moyer-Mileur et al 2013; Karbandi et al 2016).

- *Decreased stress and pain*: massage interventions provided prior to skin-breaking procedures (e.g. venipuncture) have been shown to decrease infant biobehavioural responses to pain (Mater et al 2019).

- *Improved immune function*: the provision of infant massage has also been demonstrated to have positive effects on infant immune function, in relation to both increased natural killer cell cytotoxicity and reduction in incidence of sepsis (Ang et al 2012; Mendes and Procianoy 2008).

- *Improved neurological development*: massage therapy has been shown to influence short- and longer-term outcomes in preterm infants. Procianoy et al (2010) showed that preterm infants <32 weeks' gestation who received massage had higher mental and psychomotor scores at 2 years' corrected age. Abdallah et al (2013) also demonstrated improved cognitive scores of preterm infants who received massage at 12 months' corrected age.

- *Enhanced feeding outcomes*: the provision of massage therapy is evidenced as supporting the development of early feeding behaviour leading to earlier establishment of full oral feeding and higher rates of milk consumption (Fontana et al 2018; Fucile et al 2011).

- *Enhanced parent–infant relationships*: a systematic review demonstrated the supportive function of infant massage in relation to the mitigation of maternal distress, the results of which were shared across diverse parent cohorts (e.g. cocaine-exposed infants, mothers experiencing depression, and grandparent volunteers etc.) (Galanakis et al 2015).

- *Decreased length of stay*: a range of studies has provided evidence that the provision of neonatal massage can decrease infant length of stay by four to seven days (Wang et al 2013, Rad et al 2016).

Important to note:
The use of specific massage techniques with infants admitted to a neonatal unit must only be conducted if the occupational therapist has completed specific post-registration training and/or certification for the use of massage techniques with this population. This is not considered the same level of training as provided by a range of infant massage training providers who are focused on the well newborn population (e.g. International Association of Infant Massage). Specialist training in the provision of neonatal massage needs to encompass a range of key knowledge areas, including:

- neonatal care theories (e.g. developmental care, trauma-informed care)
- brain and sensory development
- infant anatomy and lymphatic system
- infant sleep and state regulation
- positioning and handling of the high-risk infant
- infant individualised caregiving
- parent experience in the NICU
- skin and touch in the neonatal period
- chemical exposures in the NICU and chemosensory/tactile impacts on high-risk infants (including selection of oil)
- respiratory compromise
- specific touch and massage techniques and the indications and contraindications for each.

It is also recommended that any occupational therapist incorporating neonatal massage into their NICU practice ensures that they develop a local evidence-based guideline in collaboration with the broader neonatal multidisciplinary team. This should take into account recommendations for suggested postmenstrual age for inviting parent participation in infant massage; infant co-morbidities/contraindications for use of massage interventions; individualised approaches to massage provision; the selection of an appropriate oil/medium for use; and the delivery of massage as a component of an overall parent–infant supportive engagement approach. It is also recommended that an individualised risk assessment is conducted for each infant and their family when considering the inclusion of specific neonatal massage techniques within an occupational therapy intervention.

Occupational therapists without specialist neonatal massage training may still support parent engagement in other forms of positive touch (e.g. comfort holding), in a way that is sensitive and contingent on the infant's cues.

Touch

11. **It is recommended** that occupational therapists facilitate the provision of positive touch and infant massage* by parents/primary caregivers to decrease infant stress and improve state and physiological regulation. (Asadollahi et al 2016 [B]; Baniasadi and Hosseini 2019 [C]; Kim et al 2017 [C]; Elsagh et al 2019 [D]) [New recommendation 2022]	1B
12. **It is recommended** that occupational therapists facilitate the provision of positive touch and infant massage* by parents to decrease parent anxiety and promote parent mood and parent–infant relationship. (Shoghi et al 2018 [B]; Lotfalipour et al 2019 [C]; Afand et al 2017 [C]; Kim et al 2017 [C]) [New recommendation 2022]	1B

*NB: Please see information above in Section 5.5.1 regarding the requirement for specialist training/certification to facilitate parent-delivered infant massage with high-risk infants in the neonatal unit setting.

The specific massage techniques and modes of intervention incorporated within individual studies are described below. This is not indicative of an endorsement of these specific types/styles of intervention, nor of the mode/frequency of delivery. They are presented to ensure that occupational therapists can judiciously use the evidence base to inform their practice through providing clarity on the specific methods that the research was conducted on and the outcomes achieved. Occupational therapists must use their clinical reasoning aligned with the training and practice implications outlined above to ensure the delivery of an individualised approach to the provision of positive touch for infants and families.

5.5.2 Recommendation 11: Promoting touch and massage for infant benefit

Asadollahi et al (2016) conducted a randomised controlled trial to compare the effects of gentle human touch and massage techniques on infant stress levels. The study included 78 preterm infants who were born between 30 and 31 weeks' gestational age at birth and were on average 22–25 days' old at the time of their participation. They were randomised into three groups – control, gentle human touch (15 minutes of positive touch/comfort hold) and massage (15 minutes). The massage intervention was provided in accordance with Field et al (2006). All touch interventions were provided by the infants' mothers and were repeated daily over a five-day period. Infant cortisol levels were evaluated using urinalysis on the first and sixth day (after the intervention was completed). The results indicated that the levels of cortisol in infants in the massage group were lowered, though the difference was not statistically significant. There was a difference in the cortisol levels across the three groups, which reached statistical significance between both the massage and control groups, and the gentle human touch and control group.

Baniasadi and Hosseini (2019) conducted a quasi-experimental study using a before-and-after design to assess the effect of providing massage (tactile and kinaesthetic stimulation) on behavioural responses in preterm infants. The study recruited 45 infants who received 15 minutes per day of massage (Field massage technique, Field et al 1986) for five consecutive

days. Infant outcomes were evaluated for behavioural state, motor activity and behavioural distress. Average infant age at the time of the intervention was 32.9 weeks postmenstrual age. The results indicated significant differences after massage in relation to sleep state (with greater prevalence of sleep states and reduced awake state). Significant differences were also recorded in relation to fidgeting/crying and motor activity after providing massage.

Kim et al (2017) conducted a quasi-experimental study to evaluate the effectiveness of tactile stimulation performed by fathers on their infants, in relation to the infant's physiological responses (oxygen saturation levels, heart rate and respiration rate) and fathers' perceived levels of attachment to their infants. The design used a control group and a pre-post test design. Forty father and infant dyads participated in the study – 20 in the control group and 20 in the tactile intervention. Infants included were those born at >30 weeks' gestational age. The intervention was provided by fathers and was of 10 minutes' duration and implemented daily for five consecutive days. The intervention consisted of gentle stroking with moderate pressure on various parts of the body (as described by Field 2001). Fathers were trained to observe avoidance cues and signs of distress. The study results indicated significant differences between the experimental and control groups. The infants receiving the intervention showed significantly greater oxygen saturation levels and lower heart rate and respiratory rate. Significant differences were also found in the experimental group's paternal attachment scores.

Elsagh et al (2019) conducted a randomised controlled trial to determine the effects of neonatal massage with prone positioning in preterm infants on infant heart rate and oxygen saturation levels. The study included 75 infants who were between 33 and 37 weeks postmenstrual age and were randomly allocated to either a massage intervention group (15 minutes daily), a prone positioning group (one hour daily) or a control group. The intervention was administered for five consecutive days and used the superficial stroking with moderate pressure method (based on T Field 1986). Statistically significant differences in the physiological measures were observed, with both the prone positioning and massage interventions serving to reduce infant heart rate and increase oxygen saturation levels.

Evidence overview

The evidence supporting the benefits to infants of receiving positive touch and/or massage provided by their parent/primary caregiver is low–moderate. Individual studies have recorded improved outcomes for infants compared with standard care in relation to a range of physiological measures, including heart rate, respiratory rate, oxygen saturation levels and cortisol levels. This recommendation is supported by two randomised trials and two quasi-experimental studies.

5.5.3 Recommendation 12: Promoting touch and massage for parent benefit

Shoghi et al (2018) conducted a randomised controlled trial to determine the effects of massage provided by mothers on maternal attachment behaviours of infants hospitalised in an NICU. The study recruited 40 mother–infant dyads who were randomly allocated to a massage or a control group. Infants were between 34 and 37 weeks postmenstrual age. After training, mothers provided the massage intervention for 15 minutes per day over a five-day period. Maternal attachment was measured using the Maternal Attachment Behaviors Scale at one hour post massage when mothers were preparing for breastfeeding. Attachment in the control group was also assessed during preparation for breastfeeding. Results showed that the study groups were comparable at baseline. Statistically significant

differences were observed between baseline and post intervention on the frequency of maternal attachment behaviours for both groups. A significant between-group difference also existed post intervention in maternal attachment between the intervention and control groups.

Lotfalipour et al (2019) conducted a quasi-experimental study to determine the effect of preterm infant massage provided by mothers on mothers' mood state. The study included 52 mothers of preterm infants who had been born between 30 and 37 weeks' gestation. Participants were randomly assigned to an intervention or control group. Mothers in the intervention group were provided with training and then invited to perform 15 minutes of massage with their infants over five consecutive days. Mothers in both groups completed the Profile of Mood State (POMS) questionnaire before and after the intervention period. Maternal mood profiles were comparable at baseline. Following the intervention, maternal mood increased in both groups; however, it showed significantly greater improvement in the intervention group.

Afand et al (2017) conducted a quasi-experimental clinical trial that evaluated the effect of infant massage on anxiety in mothers of preterm infants discharged from the NICU. The study included 70 maternal–infant dyads scheduled to be discharged from the NICU within 24 hours. Allocation to intervention and control groups was alternated weekly. Mothers allocated to the intervention group were trained in how to use the massage technique (based on that outlined by T Field 1986) and then performed 8-minute sessions with their infants on two consecutive days prior to the infant's discharge. Maternal anxiety was measured using the State-Trait Anxiety Inventory Scale. The results indicated that the mean scores of maternal state anxiety in mothers in the massage group were significantly lower than in the control group, but results were similar in terms of overall severity of maternal state anxiety.

As outlined in the previous section, a quasi-experimental study by **Kim et al (2017)** evaluated the effectiveness of tactile stimulation performed by fathers on their infants in relation to the infant's physiological responses (oxygen saturation levels, heart rate and respiration rate) and fathers' perceived levels of attachment to their infants. Forty father and infant dyads participated in the study – 20 in the control group and 20 in the tactile intervention. Paternal attachment was measured by the Paternal Attachment Scale. Results indicated significant differences between the experimental and control groups' paternal attachment scores. Significant differences were noted in six of the seven subscales, including visual awareness of the newborn; awareness of distinct characteristics of the newborn; attachment perceived as 'perfect'; strong feelings of attachment to the newborn; experience of extreme elation; and role perception as a father. The authors concluded that tactile-based interventions may be effective in the development of father–infant attachment.

Evidence overview

The strength of evidence supporting the benefits to parents of positive touch and/or massage provided to their infant during a neonatal unit admission is low–moderate. Individual studies have recorded improved outcomes for parents in comparison to standard care in relation to mood, anxiety and the parent–infant relationship for both mothers and fathers of high-risk infants. This recommendation is supported by one randomised trial of moderate quality and three quasi-experimental studies of low quality.

Occupational therapists play a key role in supporting parents to engage in positive touch interventions to support both their infant's regulatory and physiological state and their own wellbeing through participation in meaningful, nurturing, caregiving occupations. However, as noted previously, occupational therapists must ensure that they are appropriately trained to support parents to engage in these activities. Positive touch interventions should only be provided by using a sensitive, individualised approach in accordance with the infant's behavioural cues.

5.6 Postural support

5.6.1 Introduction

The delivery of developmental care for infants in the neonatal unit includes the use of individualised postural support strategies for infants. Postural support and handling are two essential components of the care of infants in the neonatal unit (Vergara and Bigsby 2004). An infant's position may have a positive or negative effect on various body systems, including autonomic/physiologic, neuromotor, state, interactive and self-regulation. The use of appropriate, supportive postural management will promote self-regulation and facilitate an infant's participation in normal sensorimotor experiences, such as bringing their hand to their mouth and face (Vergara and Bigsby 2004). Conversely, inadequate or incorrect postural support may contribute to physiological instability, behavioural disorganisation, soft-tissue integrity and postural alignment (Vergara and Bigsby 2004).

The goal of postural support in the neonatal unit is 'to provide postural and self-regulatory supports that normalize infants' sensorimotor experiences as much as possible while accommodating the many constraints imposed by their medical conditions and environment' (Vergara and Bigsby 2004, p183). The provision of postural support aims to deliver a non-intrusive intervention that enables infants to develop adaptive responses similar to those of term infants. This is achieved through the use of positioning aids, of which both commercial and bespoke options are available. The key goals of neonatal positioning (Vergara and Bigsby 2004, p187) are to:

- provide containment and a sense of security for a smoother adjustment to the extrauterine environment
- discourage extension and promote flexion to achieve postural and movement patterns that resemble those of healthy term infants
- optimise physiological stability and neurobehavioural organisation to enhance infant self-regulation
- promote hand-to-mouth activity to enhance the infant's ability to self-calm
- maintain proper body alignment to prevent postural asymmetries
- expose the infant to a variety of postures to prevent the development of fixed postural patterns
- maintain skin integrity and prevent skin breakdown
- maximise the infant's developmental potential and engagement in family-expected age-appropriate occupations.

By considering each infant's specific cot environment and assessing an infant's neurobehavioural cues, occupational therapists can identify postural support recommendations that will best support each infant. Implementing postural support techniques that are specific to each infant has been shown to promote infant motor outcomes, improve their self-regulatory behaviours and prevent compromise of their breathing. The postural support recommendations refer to interventions provided to high-risk infants within the neonatal unit. All infants must be transitioned to established safe-sleep principles, such as those promoted by the Lullaby Trust (c2020), prior to their discharge from the neonatal unit.

Postural Support	
13. **It is recommended** that occupational therapists collaborate with the neonatal team to facilitate individualised postural support recommendations for infants that promote infant motor outcomes, self-regulatory behaviours and prevent respiratory compromise. (Lai et al 2016 [A]; Santos et al 2017 [B]; Kochan et al 2019 [B]; Gouna et al 2013 [C]; Grenier et al 2003 [C]; Liaw et al 2012 [C]; Nakano et al 2010 [C]) [Statement amended and new evidence 2022]	1C
14. **It is recommended** that occupational therapists review the selection and use of neonatal postural support aids for their ability to promote infant motor outcomes, the development of infant postural control and self-regulatory behaviours. (Madlinger-Lewis et al 2015 [B]; Zarem et al 2013 [C]) [Statement amended 2022]	1B
15. **It is recommended** that occupational therapists use a postural support assessment tool to support the education of the neonatal team and promote individualised positioning of high-risk infants in the neonatal unit. (Coughlin et al 2010 [D]) [Statement amended 2022]	1D

5.6.2 Recommendation 13: Individualised postural support recommendations

Gouna et al (2013) conducted a cohort study to compare breathing patterns and respiratory variables measured in supine, left lateral and prone positions in preterm infants. The study included 19 infants (gestational age 26–30 weeks) from a single neonatal unit in France. Respiratory variables were recorded for three hours after each position change experienced by the infant following a feeding interval. The results demonstrated that the fraction of expired oxygen was similar across all three positions. Arterial oxygen levels and lung volume were higher in the left lateral and prone position than in supine. The authors concluded that the left lateral and prone positions improve pulmonary function by optimising ventilatory strategy and lung volume.

Santos et al (2017) explored the impact of infant sleeping position on the physiological and behavioural effects of preterm infants being cared for in a neonatal unit. Using a quasi-experimental study design, 24 preterm infants (≤32 weeks' gestational age at birth) were

randomised into four groups: right side position, supine, left side position and prone. All positions incorporated body and head alignment, midline position, upper limb flexion and lower limb support. Physiological and behavioural variables were evaluated before, during and after positioning. No significant differences in heart rate, respiratory rate or peripheral oxygen saturation levels between the four positions were noted. The median state response for infants in all positions was either deep or light sleep, though behavioural scores were lower in supine, left-side-lying and prone. The authors conclude that practitioners may use a variety of positions to support infants, but it is important that approaches to ensuring flexion, alignment and containment are maintained.

A retrospective cohort analysis conducted by **Grenier et al (2003)** examined the existence of a relationship between preterm infant position and the frequency of motor-based self-regulatory and stress behaviours. The study included 15 infants born between 23 and 30 weeks' gestation recruited from a single neonatal unit in the United States. Infants were observed during non-caregiving periods, with their behaviours categorised as those that suggested stress or motor efforts of self-regulation. The number of motor self-regulatory and stress behaviours observed in the infants was related to infant position, with the highest ratios of behaviours observed when the infants were side-lying and un-nested, and the lowest observed in a prone, nested position. The incidence of more self-regulatory and stress behaviours was related to longer periods of fussing and crying. Longer periods of light sleep were related to fewer stress behaviours. Infants were observed to perform the fewest stress behaviours in prone nested, prone un-nested or side-lying nested. The authors concluded that these positions may benefit infants in the neonatal unit by reducing their need for motor-based self-regulatory behaviours, thereby potentially conserving energy for growth.

Kochan et al (2019) conducted a randomised controlled trial to evaluate the effect of elevated midline head position on cardiopulmonary function and the incidence of periventricular-intraventricular haemorrhage (PIVH) in preterm infants. The study included 180 extremely low birthweight infants (birthweight <1000 grams) who received a cranial ultrasound within four hours of birth. The infants were randomised to either standard care (flat – indicated as supine position with the cot in a flat position and turning of the head 90 degrees right or left every four hours) or the study position (elevated – indicated as supine position with elevation of the head/body 30 degrees above the horizontal with the head maintained in the midline) for the first four days of life. The group cared for in the elevated position developed significantly fewer grade 4 haemorrhages and survival to discharge was significantly higher than in the control group. Additionally, no significant differences were seen in the incidence of bronchopulmonary dysplasia or other respiratory complications.

Liaw et al (2012) conducted a cohort study which explored the effects of 24-hour caregiving, positioning and the use of non-nutritive sucking in the neonatal unit on preterm infants' sleep and wake states, and identified factors associated with state changes. Thirty infants (27–37 weeks' gestation) were recruited from a single neonatal unit in Taiwan. Infants had increased occurrences of quiet sleep when they were not interrupted for caregiving and were positioned in side-lying.

Nakano et al (2010) conducted a cohort study to evaluate how a positioning programme influenced the movement patterns of preterm infants. Twelve infants were recruited for the study from two neonatal units in Japan. Infants were positioned with the support of a nesting aid in either supine, prone or side-lying. Spontaneous infant movements were recorded when the infants reached 38–39 weeks' postmenstrual age. The study findings

indicated that the velocity of movements of the positioning group had more variability than those of the control group, with increased incidence of hands brought together. The authors concluded that infants who had received positioning support exhibited movement patterns similar to those of term-born infants.

Finally, **Lai et al (2016)** conducted a systematic review on the effectiveness of co-bedding compared with separate (individual) cots for stable preterm twins in the neonatal nursery in promoting growth and neurodevelopment and reducing short- and long-term morbidities. The review also aimed to determine if co-bedding was associated with adverse effects. Five RCTs were included in the review. The authors noted that four of these were of low quality with small sample sizes, and the majority of the data was contributed by one large RCT. No differences were reported between co-bedded and individually bedded preterm twins in relation to rate of weight gain; apnoea, bradycardia and desaturation episodes; episodes in co-regulated states; incidence of suspected or proven infection; length of hospital admission; or parent satisfaction. The authors concluded that the current evidence for the benefits and harms of co-bedding stable preterm twins is insufficient to specify recommendations for practice.

Evidence overview

The goals of neonatal postural support with the preterm infant include movement, containment and comfort, and promoting flexion. It also aims to prevent head flattening and external rotation of the hips, and to prevent asymmetrical posture with alignment through the promotion of midline orientation. This position is also beneficial for supporting the infant's self-regulation. Occupational therapists can promote the use of individualised postural support recommendations for infants on the basis of neurobehavioural assessment. Individualised infant postural support has been demonstrated to promote infant motor outcomes, improve infant self-regulatory behaviours, decrease the incidence of severe brain haemorrhage and prevent respiratory compromise. This recommendation is supported by one randomised controlled trial, one quasi-experimental trial, one systematic review (with inconclusive findings) and four cohort studies, leading to a moderate level of evidence.

5.6.3 Recommendation 14: Neonatal postural support aids

Madlinger-Lewis et al (2015) conducted a randomised controlled trial to investigate the effects of a new positioning device compared with traditional positioning methods used with preterm infants. The study included 100 infants (born <32 weeks' gestation) from a single neonatal unit in the United States. Infants who had been nursed using the positioning device demonstrated less asymmetry of their reflex and motor responses compared with those who had used traditional positioning methods.

A survey conducted by **Zarem et al (2013)** explored the perceptions of neonatal nurses and therapists of different methods of positioning used in the neonatal unit. Seventy-six staff participated in the survey and were employed in one neonatal unit in the United States. Both nurses and therapists agreed on the importance of positioning for the wellbeing of preterm infants. They differed in their perceptions of the use of commercial versus traditional positioning techniques in relation to promoting sleep. Staff reported their preference for a commercial device which was perceived to be the easiest to use in terms of placing the infant in good alignment.

Evidence overview

Infant positioning can be supported through the use of commercial and bespoke positioning equipment. At present, there is no definitive evidence promoting one type of positioning device over another. When developing positioning recommendations for high-risk infants, occupational therapists should ensure the individualisation of the recommendations in order to promote more symmetrical postures and improved self-regulation in infants. This recommendation is supported by one randomised controlled trial and one qualitative/questionnaire study, which collectively are considered a moderate level of evidence.

5.6.4 Recommendation 15: Postural support assessment tools

Coughlin et al (2010) completed a cohort study which aimed to develop a positioning assessment tool that could be used to standardise best practices in neonatal positioning and evaluate its effectiveness in teaching consistent positioning practice. The Infant Positioning Assessment Tool (IPAT) was implemented in six neonatal units in the United States and used as part of a training package about developmentally supportive interventions. The positioning assessment tool was used as a baseline measure and following receipt of staff training. The post-training evaluation demonstrated significantly higher positioning scores in each of the neonatal units. All infants assessed during the post-training evaluation were optimally positioned.

Evidence overview

Infant positioning can be supported through the use of a positioning tool on a routine basis to facilitate staff education and the implementation of individualised positioning recommendations for infants. This recommendation is supported by one cohort study of low-quality evidence.

5.7 Infant feeding

5.7.1 Introduction

Feeding is one of the primary occupations of infants. When learning to feed, an infant is also engaged in a shared experience and scaffolding relationship with their family (Vergara and Bigsby 2004). Although feeding is a dependent task for infants, it is one in which they engage in a co-occupation with their parent. They are active participants in feeding activities. Infants learn to feed through a dyadic relationship with their caregiver. For feeding success, this involves an interplay between the infant adaptively responding to the caregiver's feeding style and the caregiver responding to the infant's feeding style (Vergara and Bigsby 2004).

Infants receiving care in the neonatal unit may experience feeding difficulties. This is particularly the case in infants who experience gastroesophageal reflux or have chronic lung disease or neurological complications, but is also common among preterm infants without these concerns (Thoyre 2007). When infants in the neonatal unit are ready, oral feeding will be gradually introduced. Supporting early and consistent parent involvement in feeding begins the learning process and development of the feeding relationship between the parent and their infant prior to and in preparation for the transition to home.

Parents will work with a range of professionals during this time (e.g. nurse, speech and language therapist, lactation consultant) as their infant matures and develops new skills in relation to feeding. Occupational therapists can also make a contribution in supporting the development of infant feeding in the neonatal unit and following transition to home.

Occupational therapists provide specific interventions to support infant feeding in relation to supporting caregivers to read, interpret and respond to infants' cues, and to assess and support early sensorimotor development influencing feeding readiness. When infants in the neonatal unit are ready, oral feeding will be gradually introduced.

Supporting early and consistent parent/caregiver involvement in feeding begins the learning process and development of the feeding relationship between the parent and their infant prior to and in preparation for the transition to home. Occupational therapists can support this transition by recommending appropriate positioning for parent and infant, plus equipment required, and/or recommending behavioural adaptation as appropriate to meet the individual needs of the caregiver and the infant to support positive and developmentally appropriate feeding experiences.

Occupational therapists' knowledge of assessing and supporting self-regulatory capacities of high-risk infants enables them to support parents to read and respond appropriately to their infant's neurobehavioural cues prior to, during and following feeding, to enhance the feeding experience for both babies and their parents/caregivers. This has been shown to help build parents' confidence around feeding after discharge to home (Ross and Browne 2013).

Infant feeding

16. **It is recommended** that occupational therapists collaborate with the neonatal team to support parents in reading and responding to infant feeding readiness cues to promote the co-occupation of feeding in the neonatal unit and following transition to home. (Ross and Browne 2013 [B]; Brown and Pridham 2007 [C]; Caretto et al 2000 [C]; Mitha et al 2019 [C]; Maguire et al 2018 [C]; Swift and Scholten 2010 [C]; Ward et al 2000 [C]; Chrupcala et al 2015 [D]; Waitzman et al 2014 [D]) [New evidence 2022]	1C
17. **It is recommended** that occupational therapists promote an appropriate environment in the neonatal unit to support parent/infant participation in early feeding experiences. Environmental support factors may include space, seating, privacy, sensory environment and NICU culture. (Flacking and Dykes 2013 [C]; Pickler et al 2013 [C])	1C

5.7.2 Recommendation 16: Supporting infant feeding readiness

Ross and Browne (2013) conducted a systematic review which aimed to ascertain the evidence on breastfeeding rates, feeding skills or problems, and growth outcomes in preterm infants at the time of discharge from the neonatal unit. The study incorporated 55 papers. The study concluded that supporting parents and infants to engage in a range of strategies that promote breastfeeding (e.g. skin-to-skin care, non-nutritive sucking, tube feeding instead of bottle feeding) was associated with improved breastfeeding rates, including exclusive breastfeeding at the time of discharge. The majority of papers identified the decrease in breastfeeding rates over the infant's first year of life. The study also identified that at discharge, the infants in the included papers were not receiving full oral feeds, or were demonstrating some ongoing difficulties with suck–swallow–breathe co-ordination.

Finally, the authors identified that preterm infants experience delayed skills in feeding attainment, even after correcting for prematurity. This links with continuing feeding concerns for parents following discharge that require ongoing support.

Brown and Pridham (2007) conducted a longitudinal cohort study of 37 infants and their mothers which aimed to explore the contribution of adaptiveness of early maternal feeding behaviour to the adaptiveness of later infant feeding behaviour. The study was conducted in a single neonatal unit in the United States and followed infants from the onset of oral feeding until 4 months post-term age. The quality of maternal feeding behaviour in the neonatal unit was explored in relation to positive affective involvement and sensitivity/responsiveness (e.g. sensitivity, responsiveness to infant cues, expression of positive affect and enjoyment), and the mother's regulation affect and behaviour (e.g. structuring of a feeding, mediating the feeding environment, positive social-emotional experience). The study indicated the association between maternal and infant behaviours, with the quality of maternal feeding behaviours associated with the quality of infant feeding behaviour at 4 months.

A qualitative study conducted by **Caretto et al (2000)** aimed to understand the current trends in parent education related to feeding in the neonatal unit, and the role that occupational therapists play in providing education to parents. In a survey of 100 neonatologists in the United States, occupational therapists were identified as being responsible for providing parent education with regards to positioning, infant development, and infant states and cues. They were also highly engaged in supporting parental education about infant feeding.

Swift and Scholten (2010) conducted a qualitative study which aimed to develop a model to identify considerations for neonatal unit staff that would improve the delivery of family-centred care. The study included nine mothers and two fathers from a single neonatal unit in Australia, whose preterm infants experienced ongoing feeding issues at 36 weeks postmenstrual age. Parent perceptions highlighted the struggle between wanting to take their infant home, and the presence of feeding issues preventing this from occurring. This served to shift the experience of parent–child interaction and co-occupations to one of intake and weight gain. Recommendations were made for the ongoing support of infant feeding in the neonatal unit as an interactive experience between parents and their infant.

Ward et al (2000) conducted a qualitative study which aimed to explore the perceptions of occupational therapists and parents regarding services provided in the neonatal unit. The study was conducted in the United States and had a strong focus on the provision of feeding interventions for preterm infants. Mothers in this study appreciated the information provided to support feeding engagement, including oral stimulation and reading infant cues. Equally, they concurred that support was predominantly provided via hands-on demonstration and facilitation. Both mothers and therapists recognised that time availability impacted on the ability to provide consistent support during the development of early parent–infant feeding co-occupations.

Mitha et al (2019) conducted a cohort study in which they analysed hospital characteristics and breastmilk feeding policies associated with breastmilk feeding at discharge for infants who were part of the EPIPAGE-2 study (a national cohort of 833 infants born from 32 to 24 weeks' gestation). Multiple logistic regression analysis revealed that higher rates of breastmilk feeding at discharge were associated with participation in kangaroo care, the early involvement of parents in feeding support, the provision of unit training in a

neurodevelopmental care programme, and units located in geographical regions in France with higher levels of community breastfeeding initiation.

A service evaluation conducted by **Chrupcala et al (2015)** aimed to increase the number of infants in a neonatal unit who were fed according to feeding readiness cues prior to discharge and potentially decrease length of hospital admission. The evaluation was conducted in a single neonatal unit in the United States and involved 170 infants (20 infants prior to the implementation of cue-based feeding). In the ten months post-implementation, infant-driven feeding became a more integrated part of routine neonatal practice. Infants who were able to be fed according to their feeding readiness cues achieved full oral feedings more quickly, and subsequently had decreased length of stay.

Maguire et al (2018) conducted a qualitative focus group study which explored how neonatal practitioners who are expert in feeding infants with neonatal abstinence syndrome (NAS) successfully feed these infants during the period of withdrawal. Four focus groups were conducted with a total of 12 neonatal staff (ten nurses and two speech therapists). Four overarching themes were identified which were related to success with feeding infants with NAS: optimal medication management; follow the baby's cues and be flexible with techniques; calm and comfortable; nurture the relationship. The focus group provided clinical practice examples of how these attributes were used in practice, though ensuring strategies were individualised to each infant was a prevalent theme.

Waitzman et al (2014) conducted a qualitative study which aimed to examine the content validity of the Infant-Driven Feeding Scales (IDFS). The IDFS are comprised of three scales used to assess preterm infants' oral feeding readiness, measure the quality of feeding performance, guide feeding intervention and provide a standardised format for documentation. The IDFS were designed for infants who are medically stable and are 33 weeks' gestation (Waitzman et al 2014). The study recruited 12 experienced neonatal therapists who participated in a Delphi methodology to refine the language of the IDFS and improve the content validity. Language changes were made to the feeding readiness scale as a result of practitioner feedback, and existing consensus confirmed for the quality and caregiver techniques scales.

Evidence overview

The body of evidence provides support for the benefits of focusing on the parent–infant relationship during feeding to improve parent understanding of infant feeding readiness, parent confidence, parent sensitivity and sensitive introduction of oral feeding for the infant. This recommendation is supported by low-quality evidence, drawn from one descriptive systematic review, two quasi-experimental studies, two cohort studies, one service evaluation and five qualitative studies.

No specific risks were reported in any of the studies with regard to the adoption of a feeding readiness approach to the introduction of oral feeding.

Working alongside specialist neonatal colleagues, including speech and language therapists, nurses and lactation consultants, occupational therapists add to the support structure surrounding the developing parent–infant relationship. This is facilitated through supporting parents to read infant cues, providing support for the infant's developing self-regulatory capacities and considering the interplay that occurs between parents and infants during a co-occupation such as feeding. Given the involvement of occupational therapy services for infants and young children experiencing long-term feeding issues, early engagement in

supporting the occupation of feeding serves to equip parents with guidance that they can utilise after their infant's transition from hospital to home.

5.7.3 Recommendation 17: Managing the environment during infant feeding

Flacking and Dykes (2013) conducted a qualitative, ethnographic study which explored parents' practices and experiences of feeding their preterm infant, particularly in relation to the environment. The study involved 52 mothers, 19 fathers and 102 neonatal unit staff drawn from four units (two in Sweden and two in the UK). Care practices across the units ranged from couplet care to cotside chairs, with parental rooming only prior to infant discharge. The study findings provide a strong sense of the role that the neonatal environment played in the development of attuned feeding between parents and their infant. These were categories in relation to the level of ownership parents felt they had of the space and place, the feeling of 'at-homeness', the experience of a door against people entering (for privacy, for enabling a focus on the parent–infant interactions and for regulating socialising), and the window of opportunity. The findings showed that the construction and design of space and place were strongly influential on the developing parent–infant relationship and for experiencing a sense of connectedness and a shared awareness with the infant during feeding, and attuned feeding.

Pickler et al (2013) conducted a qualitative component within a randomised controlled trial to ascertain the effect of the environment (open bay and single-family room) on the volume taken in by infants who were born at 30–32 weeks of age. Environmental attributes were recorded for 87 infants during each oral feeding (from first oral feed until discharge). The study identified that typical feeding times of 9am, 12pm and 3pm were associated with the highest levels of light and sound. Conversely, feeding times of 12, 3 and 6am where light levels were moderated were associated with improved feeding outcomes. Additionally, the infant's level of wakefulness (feeding readiness cue) was associated with volume of feed taken.

Evidence overview

Two low-level studies highlight two important aspects by which the neonatal environment can influence parent–infant feeding occupations. First, that unit environment and design can impact parents' involvement in feeding. The environment provides strong cues to parents in terms of their sense of place at their infant's cotside, which plays an important role in supporting involvement in breastfeeding. Second, an infant's ability to cope with sensory input will influence the success of their feeding. It is important to consider the wider environmental context when supporting parent–infant feeding development, and incorporate environmental modifications that support an infant's self-regulatory capacities.

With a strong background in the consideration of the environment on the performance of daily occupations, occupational therapists can facilitate an appropriate environment for parent–infant feeding activities.

5.8 Parent engagement

5.8.1 Introduction

The birth of an infant who requires admission to an NICU represents a major life-changing crisis for parents, which could have an impact on the acquisition of their parenting role and engagement in parenting occupations (Gibbs et al 2015, Lavine et al 2021). Becoming parents of a full-term, healthy infant is generally experienced as a normative, developmental process. In contrast, the experience of parenting a medically fragile infant, whether full term

or premature, is very different. The experience of a high-risk pregnancy and/or the delivery of an unwell or preterm infant may cause significant feelings of stress, grief, guilt and loss of an expected newborn phase or third trimester. This may be compounded by the impact of this experience upon the infant (Lasiuk et al 2013).

That the birth of a high-risk infant may influence the acquisition of parental role and the engagement in parenting occupations is becoming more recognised in the occupational therapy literature. Dudek-Shriber (2004) identified that the most stressful aspect of having an infant in an NICU is related to altered parental role and relationship with their infant. It was recommended that occupational therapists retain a strong focus on facilitating a positive parent–infant relationship and provide interventions that focus on supporting the parents' occupational role (Dudek-Shriber 2004). Gibbs et al (2016) highlighted the impact of an occupation-based approach for parents – supporting their meaningful interaction and nurturing care of their infants resulted in the development of a greater sense of identity as a parent.

Occupational therapists can support the care provided by the neonatal multidisciplinary team, and thereafter teams delivering follow up and early intervention, by incorporating the use of occupation-centred frameworks. This approach provides a structure through which an understanding of how each infant and their family accommodate to the neonatal unit experience can be achieved and, more specifically, can be used to direct the delivery of family-centred care and support parent engagement (Gibbs et al 2010).

The role of occupational therapy is important in supporting caregivers' experience of parenting a high-risk infant, considering their previous experience – whether it is their first baby or building on previous birth experiences – and incorporating siblings and extended family into the NICU journey. It is important that occupational therapists incorporate person, environment and occupational transactions as part of the parental journey in the neonatal unit (Gibbs et al 2010). Also, occupational therapists should take caregivers' socio-economic influences into account as this may relate to parent–infant engagement (Pineda et al 2018). Leahy-Warren et al (2020) highlighted the importance of the early identification and implementation of professional involvement to ensure parents have access to formal and informal social support for parental wellbeing and infant–parent engagement.

Parent engagement

18. **It is recommended** that occupational therapists work with parents of high-risk infants to support parenting roles and relationships, and to provide sensitive and appropriate parent engagement in the infant's care in the neonatal unit. 1A

(Ding et al 2019 [A], Gibbs et al 2015 [A]; O'Brien et al 2018 [A]; Bäcke et al 2020 [C]; Dudek-Shriber 2004 [C]; Gibbs et al 2016 [C]; Pineda et al 2018 [C]; Gustafson et al 2016 [C]; Ganadaki and Magill-Evans 2003 [D]; Price and Miner 2009 [D]; Skene et al 2019 [D])
[New evidence 2022]

19. **It is recommended** that occupational therapists facilitate the development of co-occupations related to activities of daily living (including, but not limited to, feeding, bathing, nappy changing, dressing and play activities of daily living) with preterm and low birthweight infants to ensure sensitive and appropriate caregiving and promote occupational performance of infants and parents. (Chiarello et al 2006 [C]; Kadlec et al 2005 [C]; Winston 2015 [D]) [Statement amended 2022]	1C
20. **It is recommended** that occupational therapists working with families of high-risk infants build a positive therapeutic collaboration with parents to enhance parental learning about their infant both during and following the transition to home. (Aydon et al 2018 [B]; Fucile et al 2020 [C]; Harrison et al 2007 [C]; Ingram et al 2016 [C]) [New evidence 2022]	1B
21. **It is suggested** that occupational therapists explore both traditional and innovative methods (e.g. video-conferencing) of supporting families post-discharge from the neonatal unit as a means of promoting parent confidence and competence in caring for their infant following the transition to home. (Gund et al 2013 [C])	2C

5.8.2 Recommendation 18: Supporting parenting occupations/parental role

O'Brien et al (2018) conducted a multi-centre randomised controlled trial, which included 26 neonatal units in Canada, Australia and New Zealand, to analyse the effect of the Family Integrated Care (FICare) programme on infant and parent outcomes, safety and resource use. Units were randomised to provide FICare (n=891 infants) or standard NICU care (n=895 infants). Infants were born at ≤33 weeks' gestation and had no or low-level respiratory support. Infant outcomes were identified as being increased weight gain and higher exclusive breastmilk feeding rate at discharge for those in the FICare group. Parent outcomes included lower mean stress and anxiety scores for parents participating in the FICare intervention. No differences were noted between any secondary morbidity/mortality outcomes, duration of oxygen therapy and length of hospital stay. No adverse intervention effects were noted. The results of this study suggest that FICare is an important advancement in neonatal care, though more evidence is needed to explore long-term outcomes.

Ding et al (2019) conducted a systematic review and meta-analysis of randomised controlled trials in which they aimed to determine the effects of family-centred care (FCC) interventions on preterm infants and parent outcomes in the neonatal intensive care unit. Nineteen RCTs were included. The meta-analysis indicated significant improvements in weight gain, parent satisfaction, skills and knowledge of parents, parental anxiety and depression, a reduction in readmission at follow up and lower parent stress. No differences were noted in relation to infant neurobehavioural development (measured in three studies) and hospital length of stay.

Price and Miner (2009) conducted a qualitative study that explored the use of occupation-based practices by experienced occupational therapists in the neonatal unit. This study was a single case study involving one mother, one infant and one occupational therapist.

Observations of the interactions between the therapist and infant/parent, and interviews with the therapist, identified two key elements for inclusion in neonatal occupational therapy clinical reasoning. These are the importance of negotiating the meaning of parenting activities and parenting co-occupations with each family, and ensuring that opportunities are provided for parents to participate in co-occupations with their infant throughout the neonatal unit admission. Supporting this connection and opportunity for meaningful engagement with their infant also leads to the optimal conditions for promoting infant development.

A pilot cohort study, conducted by **Ganadaki and Magill-Evans (2003)**, involved ten families and aimed to explore whether there were any differences between fathers' and mothers' interaction patterns with infants and young children who were receiving early intervention services. Differences were observed between mothers' and fathers' interaction styles with their children, with mothers generally receiving higher scores in categories that relate to promoting the development of skills in their child. This is an important point when considering how occupational therapists work with both parents or primary caregivers for a high-risk infant to support the development of their own parenting role, but also in the delivery of advice and guidance that promote the development of their infant.

Gibbs et al (2015) conducted a meta-ethnographic synthesis which aimed to explore the concept of parenting as an occupation as a means of supporting parent engagement in the neonatal setting. The synthesis included 35 individual papers of qualitative research design that collectively included 453 parents (311 mothers and 142 fathers). Parents were noted to move through key transitions as they adapted to their experiences of parenting a high-risk infant: relinquishing the anticipated role of parent; feeling vulnerable and powerless; juggling roles and responsibilities; claiming an alternative parental role; navigating environmental boundaries; developing partnerships with staff; coming to know the infant; and adapting to parenting.

The findings illustrated that events leading to, and including, the birth of a preterm infant may cause significant occupational disruption to parents. As parents struggle to come to terms with the events surrounding their infant's admission to a neonatal unit, this disruption leaves a void in their developing parental identity. During the admission, parents began to participate in a process of transition as they worked to reclaim their parental role and learn new occupations associated with parenting a preterm infant. The authors identify the importance in moving the acknowledgement of parent involvement in the NICU beyond involvement in basic caregiving activities and highlight the importance of transforming parent involvement into opportunities for participation in nurturing and caring for their infants in ways that are meaningful to them.

Pineda et al (2018) conducted a cohort study that aimed to define the predictors of parent presence (including holding and skin-to-skin care) and to investigate the relationship between parent participation and early neurobehaviour and developmental outcomes at age 4–5 years among preterm infants. The study involved 81 infants born at ≤32 weeks' gestational age at birth, and parent presence and holding were tracked throughout the infant's admission. The median number of days per week in which parents were documented to be present was 4.0 and days held per week was 2.8. More parent presence was observed among mothers who were Caucasian, married, older, employed, had fewer children, had family support and were providing breastmilk for their infants. More holding was observed in infants with fewer medical interventions, who were Caucasian, had a father who was employed, and parents had fewer children and family support. More parent holding in the NICU was related to better reflex development at term age, and skin-to-skin

care was related to improved infant reflexes and less asymmetry at term, and better gross motor skills at 4–5 years. The authors conclude that social and medical factors impact parent presence and highlight the importance of engaging families in the NICU.

Gibbs et al (2016) conducted a qualitative narrative study with six parents (three couples) of preterm infants to explore the experiences that enabled them to participate in occupations associated with the role of parenting in the neonatal unit. Infants were born between 24 and 29 weeks' gestational age at birth and required between 8 and 105 days of ventilation or CPAP. Semi-structured interviews and narrative analysis revealed six themes: anticipating occupations versus reality; needing emotional resilience; working to reclaim parental role; navigating the NICU occupation–environment transactions; building and maintaining relationships with staff; and revisioning the future. The findings suggested a resonance between the occupations in which parents sought to engage and their developing perception of themselves as parents to their preterm infant. The sense of reclaiming responsibility for caregiving to support their developing occupational identity as parents was a key factor for these families. The authors conclude that the findings provide support for an occupation-based practice approach for parents of preterm infants in the NICU.

Gustafson et al (2016) conducted a quasi-experimental study to evaluate the effect of parent presence during multidisciplinary ward rounds on NICU-related parent stress. The study enrolled 132 parents with non-random allocation to the control or experimental group. Parents in the experimental group were invited to attend the multidisciplinary ward rounds for their infant for the duration of their NICU admission. Pre and post measures of parent stress, anxiety and ways of coping were measured on Day 0 and then three days later. The results indicated that parent stress scores decreased significantly in the experimental group between the pre and post time points, but the difference between the overall change in both groups was not significant. As measured on the PSS:NICU, the parental role alteration subscale showed the most change. No differences between groups were noted in anxiety or ways of coping. The authors report that parents welcomed the opportunity to participate in their infant's ward rounds and their presence did not result in increased stress.

Dudek-Shriber (2004) conducted a cohort study which aimed to determine the frequency of stress experienced by parents, the parent/infant characteristics that result in different stress scores, and the influence of parent and infant characteristics in predicting stress. The study involved 181 parents whose infants were admitted to a neonatal unit for longer than seven days. Using the neonatal unit Parent Stressor Scale (PSS; NICU) the results showed high scores of general stress, indicating that the stress experienced by parents in the neonatal unit is often diffuse. However, when looking at the individual subscales of the measurement tool, the results indicated that parents perceived that the most stressful aspect of their neonatal admission was an altered parental role and relationship with their infant.

A participatory action research study conducted by **Skene et al (2019)** aimed to develop, implement and evaluate family-centred interventions to promote parent involvement in caregiving in the neonatal unit. The practice changes that were the specific focus of the study were increased skin-to-skin contact and unlimited parent presence at the cotside. The study captured both qualitative and quantitative data to explore staff and parent perceptions of the project. Findings indicate that parent involvement in care increased throughout the project. Parents described more episodes of closeness and involvement than during the baseline period. Increases in direct physical contact were also noted, with all parents being able to hold their infant, often in skin-to-skin contact, within the first few days. Although parents initially reported feeling inadequate in their ability to care for their infant, their

confidence grew as nurses encouraged them to do more. Parents confirmed that they could be present with their infant whenever they wished, and this increased their confidence in decision making and decreased their fear of the unknown and feelings of helplessness.

Finally, **Bäcke et al (2020)** explored the experiences of parents whose infants were receiving therapeutic hypothermia (TH) after severe perinatal asphyxia, in relation to their experience of closeness and involvement in their infant's care while in the NICU. Semi-structured interviews were completed with 11 parents. The findings revealed three overarching themes that described parent experiences: parenting role (including participation, emotional chaos and being close); support in a chaotic situation (including the need for information, emotional support and ambivalent emotions); and the environment (including barriers to closeness and supporting presence). The authors concluded that parents of infants receiving TH want to be closer to and more actively involved in the care of their infants but can find it difficult to take the initiative themselves. More active guidance by NICU staff may be one way to promote parental closeness and participation during TH.

Evidence overview

Occupational therapists can make a significant contribution to the support of parents and their engagement in caregiving in the neonatal unit. A number of studies have been undertaken to explore the impact of the birth of a high-risk infant on parenting experiences, including their participation in activities/occupations that relate to their parental role. The studies have consistently identified that parents who experience the birth of a high-risk infant may find it difficult to adapt to their new role and benefit from interventions that support their increased participation in caregiving. The evidence supporting this recommendation consists of one systematic review, one multi-site RCT, one qualitative meta-synthesis, one quasi-experimental study, three cohort studies, one participatory action research study and three qualitative studies, ranging from high to very low levels of evidence.

Occupational therapists can provide a key role in supporting parents as they adapt to a different parenting role from the one they had perhaps anticipated. It is recommended that occupational therapists employ an intervention approach that supports parents' engagement in sensitive and appropriate caregiving for their infant in the neonatal unit, promoting parenting activities that will serve to build awareness of their infant's needs, sensitivity, and skills in supporting the development of their infant/child's occupations.

5.8.3 Recommendation 19: Supporting parent and infant engagement in co-occupations

O'Brien et al (2018) conducted a multi-centre randomised controlled trial which included 26 neonatal units in Canada, Australia and New Zealand to analyse the effect of the Family Integrated Care (FICare) programme on infant and parent outcomes, safety and resource use. Summary results from this study are reported in Section 5.8.2. The parents involved in the FICare arm needed to commit to having a primary caregiver at the infant's cotside for a minimum of six hours per day, five days per week. They attended medical rounds and education sessions for at least three weeks. Parents were taught skills required to provide aspects of their infant's care, such as bathing, feeding, providing skin-to-skin care, dressing, nappy changing, administering oral medications and taking temperature, as well as how to interact with and support their infant's development. They were encouraged to actively participate on ward rounds, chart their infant's growth and progress, and participate in making clinical decisions about their infant's care with the medical care team. As part of the programme of psychosocial support, parents were provided with emotional support, coping

strategies, stress-reducing activities and other assistance through informal peer-to-peer support and veteran parent and social work involvement in the education sessions. As outlined in the previous section, the results of the trial included lower mean stress and anxiety scores for parents participating in the FICare intervention.

Dür et al (2018) conducted a qualitative focus group study with 36 parents of preterm infants to explore meaningful activities of parents of very low birthweight (VLBW) preterm infants to understand their clinical relevance and foster their consideration in clinical practice and research. The findings indicated activity-related themes which were found to be important to parents of VLBW preterm infants: a change in the meaning of their activities; a transition from a feeling of parental immaturity to a feeling of maturity; a transition from following healthcare instructions to possessing healthcare skills; and a transition from a functioning-only state to a balance of activities. The findings also revealed that the meaning that parents ascribe to different caregiving activities can change over time, and that engagement in these meaningful activities can assist in fostering these transitions.

Cardin (2020) conducted a phenomenological study exploring the concepts of occupational and co-occupational performance in the NICU to provide expanded descriptions of parent–infant occupations in this setting. Fourteen parents participated in individual semi-structured interviews. The findings revealed five themes of active occupational engagement. These were (1) perceiving 'they' versus 'I', (2) maintaining proximity, (3) expressing emotions, values and beliefs, (4) addressing health issues, and (5) analysing. A matrix framework was also generated which maps the emergent themes against definitions and exemplars of parent occupations, infant occupations and parent–infant co-occupations.

The findings indicate the multifaceted and complex nature of occupation, including the challenges of defining occupation in the NICU context. The importance of meaningful engagement was highlighted but noted to include not only the execution of directly observable caregiving activities and tasks but also involvement in ordinary and often unseen events that extended over time. As such, family life as it is lived in the NICU moves beyond observable interactions and is patterned with many doing, being and becoming occupations. The author concludes that recognition of occupation's expansiveness is key in neonatal practice and these findings can support neonatal occupational therapists to redefine occupation-based practice in this highly complex environment.

Kadlec et al (2005) conducted a descriptive correlational study which aimed to examine the caregiver–child interaction qualities associated with activities that were part of daily routines of children born prematurely or of low birthweight, with or without white matter disorder, as well as children born at term. The study included 36 pairs of caregiver–child dyads and the study was undertaken when the children were 30 months of age.

As expected, children who had been identified with white matter disorder had a lower performance on both the cognitive and motor scales of the Bayley Scales of Infant Development, supporting their identification as a group of infants at increased risk for emerging developmental concerns who benefit from follow up and early intervention.

The study looked specifically at caregiver positive engagement and caregiver directiveness. For children born at low birthweight (with and without white matter disorder), positive engagement by their caregivers was moderately to strongly correlated with caregiver directiveness. This association was not observed in the group of children born at term. These findings suggest their caregivers may be adjusting the level of their social and emotional assistance during caregiver–child interactions to the level of their children's

abilities. By being both positive and directive, these caregivers may be interacting in ways that facilitate and sustain their child's engagement with activities.

Chiarello et al (2006) conducted an observational study with 20 children and their mothers and fathers. The aim of the study was to compare motor behaviour, playfulness and parent–child interactions during mother–child and father–child play in children who were experiencing motor delay. Observations were carried out when the children were 3 years of age.

Six of the children within the study were noted to perform differently depending on which parent they were interacting with. In some cases improved performance was noted with mothers, and in other cases with fathers. Overall, there were no real differences in motor behaviour performance with either parent. Mothers and fathers demonstrated similar levels of achievement, orientation, affect/affirmation and directiveness, while mothers were noted to be more responsive. The findings of this study indicate the importance of including both parents, where possible, in occupational therapy service provision, due to the strengths and skills that both bring to supporting their child's development in participating in early self-care and play occupations.

A qualitative study, which formed a component of a larger mixed-methods project, was conducted by **Winston (2015)** to examine the lived experience of mothers who were mothering a young child with feeding difficulties. The study included five women, whose children were between 12 and 36 months of age. Two emergent themes from the study findings were presented in detail: dealing with the system; and the complexity of feeding. Both of these themes revealed strong connections with maternal work and perceptions of maternal role around the negotiation of mealtimes with their children. Ongoing feeding issues arise for some children who have experienced admission to a neonatal unit. It is important to consider how best to support families who experience this, particularly in support of the parent's own occupations.

Evidence overview

There is growing evidence on both the strategies for and the importance of supporting parent participation in meaningful caregiving activities (occupations) with their infants during a neonatal admission. For children with emerging or ongoing developmental concerns there are also differences in how parents interact with them and promote optimal development. Parents report requiring additional support when their child has specific occupational performance concerns (e.g. participation in feeding). Children of parents/caregivers who can provide sensitive nurturing and appropriate facilitation of their child provide optimal conditions for supporting the development of early self-care, play and learning occupations. This recommendation is supported by evidence of high to very low quality.

Occupational therapists can facilitate parents' engagement in sensitive and appropriate caregiving both in the neonatal unit and beyond, supporting parenting awareness of their infant's needs, sensitivity and skills in enhancing the development of their infant/child's occupations.

5.8.4 Recommendation 20: Supporting parents post-discharge

Aydon et al (2018) conducted a qualitative study which explored the experiences of parents with babies born at 28–32 weeks' gestation during transition through the neonatal intensive care unit (NICU) and discharge to home. Twenty couples (40 parents) participated

in interviews (face to face and telephone) and an online survey, pre and post-discharge from the neonatal unit. Themes that overlapped both phases of the data collection were: effective parent–staff communication, feeling informed and involved, and being prepared to go home. The authors noted that neonatal professionals should ensure that parents feel that they have received effective education that will support their preparation for transition to home. However, care should be taken that information provision is not overwhelming for families and is presented consistently and with reinforcement when required. Finally, the authors argue that it is important for neonatal professionals to understand and support the potential anxiety that parents may feel prior to discharge from the neonatal unit. Identified supportive strategies include: improvements in information transfer, the promotion of parent contact with the multidisciplinary team, encouragement of input from fathers to identify their specific needs, and facilitation of parent involvement based on the individual needs of families.

Fucile et al (2020) conducted a qualitative study using a questionnaire to understand the goals of parents whose infant was in the neonatal intensive care unit (NICU) to enhance collaboration between parents and healthcare professionals. Questionnaires were distributed to 23 parents, with 13 responses returned. Parents were asked to identify goals for their child over the following two-week period. These responses were analysed thematically. Three key themes were identified in relation to the parent-articulated goals: feeding and weight gain, eliminating medical equipment, and successful hospital discharge. Specific goals that parents identified related to preparing for caregiving independence, having a period at home prior to further needed interventions, and providing the care needed to optimise their infant's development.

Ingram et al (2016) conducted a pre-post design study to investigate the effect of implementing a parent-oriented discharge planning intervention for preterm infants in neonatal care. Data to evaluate the effects of the intervention were collected during two 11-month periods, before and after implementation. 'Train-to-home' is a family-centred discharge package to increase parent involvement and understanding of their baby's needs, using a train graphic to articulate supporting pathways to facilitate parents' understanding of their baby's progress and physiological maturation, combined with estimation of the likely discharge date.

Data was collected on parental self-efficacy, infant hospital length of stay and healthcare utilisation in the 8 weeks following discharge. Two hundred and forty-five families participated in the study. There were no significant changes in parental self-efficacy and hospital length of stay between the two study phases. It was noted that in the post-implementation phase, more infants were being discharged home on mixed breastmilk and formula feed as opposed to exclusively formula feeding. There was a significant decrease in hospital emergency room attendances for infants in phase 2 of the study with associated decreases in healthcare utilisation costs. There were no differences in relation to hospital readmissions, outpatient appointments or primary care attendances. Although limited change was noted in the outcome measures, parents reported that the programme improved their understanding of their baby's progress and preparedness for discharge and therefore warrants further study and adoption.

Harrison et al (2007) conducted a qualitative study which aimed to describe how mothers feel therapists help them learn about their child with special needs, and how their learning is affected by their relationship with their child's therapist. The study was conducted in Canada and incorporated nine mothers of children aged 19 months to 5 years who were receiving therapy services in an early intervention setting.

Mothers identified that a positive relationship served to enhance their learning from their child's therapist. Two specific themes were presented in detail: relationship (both the therapist's relationship with their child, and the parent valuing their expertise and emotional support); and learning (including the provision of learning in a variety of ways and how the strength of the relationship influenced the successfulness of learning).

Evidence overview

There is moderate to low-level evidence to support the association between a positive relationship between parents and providers and strategies which enhance parent understanding of their infant's progress and the impact of these on the parent response to preparedness for transition to home and learning strategies that support their child's development. The evidence for this recommendation is drawn from one pre-post quasi-experimental study and three qualitative studies.

Occupational therapists also provide post-discharge services to high-risk infants who have been identified as having ongoing developmental concerns. They can provide a key role in supporting parents who are accessing ongoing therapies for their infant. Building a positive, collaborative relationship with parents has been shown to enhance parents' learning about their infant in relation to how they could support their development.

5.8.5 Recommendation 21: Models of service delivery

In a randomised controlled trial, **Gund et al (2013)** aimed to investigate whether the use of video-conferencing or a web application improved parent satisfaction in taking care of a preterm infant at home, thereby decreasing the need for home visits, and to explore nurses' attitudes to the use of technology. Conducted in Sweden, the study included 34 families. Video-conferencing was conducted using Skype, and the web application was a platform that allowed parents and nurses to communicate and exchange health-related information.

The parents who were using the web application or video-conferencing found them to be useful, increasing their confidence in caring for their child. While the authors concluded that these types of technology may be a relevant tool to support resource management in providing ongoing support and care for families following discharge from the neonatal unit, they did acknowledge that some staff were reluctant to engage with the technology.

Evidence overview

The potential and use of mobile health (m-Health, or the use of web-based and telephone communication) technologies in improving healthcare delivery and outcomes is of increasing interest. m-Health applications provide a novel way of delivering healthcare information to people who access services.

There is low-level evidence from a single, small, randomised controlled trial to suggest that consideration of the use of m-Health applications as a means of providing support for families as they transition home from the neonatal unit supports parents' competence and confidence in caring for their infant.

It is suggested that occupational therapists consider the strategies and service delivery models they employ when partnering with parents to build an ongoing relationship and a facilitatory learning environment.

5.9 Parent support

5.9.1 Introduction

In recognition of the importance of parent–infant attachment, there has been increasing focus on the implications of an NICU admission on the development of the parent–infant relationship. A review of the research conducted into preterm infant–parent interaction identified a range of factors that impact the development of this relationship (Bozzette 2007). In the development of reciprocal social interaction with their preterm infants, parents are often required to carry the major load of the interaction, with increased vocalisation and smiling in an attempt to engage the infant. Parents may also perceive their preterm infants as more vulnerable than term infants and engage in compensatory parenting strategies. Support for early efforts of parents to become acquainted sensitively with their infants was noted to be extremely important (Bozzette 2007).

The NICU has been acknowledged as a difficult place to establish meaningful and positive parent–infant interaction (Moehn and Rossetti 1996). The impact of the medical environment required to support such vulnerable infants in the neonatal unit contributes to the difficulties many infants experience with self-regulation and organisation. This can result in the disruption of two of the critical attributes of parent–infant attachment: proximity and reciprocity.

There is also increasing understanding of the specific influences a preterm birth and neonatal unit admission may have in the development of parent–infant relationships and later child development. Treyvaud et al (2009) specifically explored the impact of parenting behaviour on the early neurobehavioural development of very preterm infants. Key findings of this study indicated a strong, positive association between parent–child synchrony and child cognitive development and social-emotional competence at 2 years' corrected age. The researchers determined that the synchronicity of the interactions between the parent and child was a significant attribute – relating to how well the parent and child responded to each other, and dependent upon the parent's understanding of how to communicate effectively with their child (Treyvaud et al 2009).

An infant's admission to an NICU can also be a period of intense stress for parents, arising from the premature birth and medical sequelae. Studies have examined the prevalence of maternal psychological distress and parenting stress following the birth of a very low birthweight preterm infant. Singer et al (1999) identified that mothers of high-risk preterm infants reported higher levels of psychological distress than the low-risk or term infant mothers, particularly in relation to depression, anxiety and obsessive-compulsive behaviours.

Parenting stress was also high in the mothers of high-risk preterm infants and continued until the children were 3 years old. This was reflected in the participants' perception of their children as more distractible, hyperactive and demanding. Given the often continued involvement of occupational therapists in providing follow-up services to preterm infants and their families, this longitudinal impact may continue to influence the development of parent–therapist partnerships in the outpatient and community setting. Mothers of both high- and low-risk preterm infants also reported higher levels of family stress that continued until the infants were 2 years old, in comparison with the mothers of term infants (Singer et al 1999). Similarly, 20% to >40% of parents whose infants had been admitted to an NICU report clinically significant symptoms of depression, though incidence decreases over time (Segre et al 2014, Pace et al 2016). The presence of anxiety symptoms has also been noted, with presentation ranging from mild (30.3%) to moderate

(17.4%) to severe (10.3%) (Segre et al 2014). Pace et al (2016) identified that approximately 50% of both mothers and fathers experience anxiety symptoms during a neonatal admission.

In a qualitative study, Ireland et al (2019) explored the perspective of parents who had infants born extremely prematurely or with a complex antenatal surgical diagnosis. Parents expressed feelings of guilt, disempowerment, grief and loss. Lundqvist et al (2019) found that parents' lived experience of having a preterm infant cared for at the neonatal unit until discharge from hospital-based neonatal home care was varied. Mothers experienced more physiological reactions that trigger feelings of loneliness and guilt and difficulties in combining their role of mother and partner. Fathers faced conflicts in managing partners' demands, family challenges and employers who claimed time and energy.

The presence of parent stress and mental health issues has also been demonstrated to be linked to family functioning. The Treyvaud et al (2011) investigation indicated that 21% of parents of very preterm infants reported clinically significant symptoms of mental health issues at two years post birth, with a high representation of mothers among this group. Parent mental health problems at two years were also found to be associated with higher parental stress.

There is an increasingly strong picture emerging of the potential for high rates of psychological distress among NICU parents. Accompanied by the potential for preterm infants to experience lifelong medical and/or developmental issues, this provides a strong driver to continue to work to incorporate family-centred care both into the policies, procedures and culture of the neonatal unit (Gooding et al 2011) and into the provision of neonatal occupational therapy services. This approach is also a key action of the NHS England Neonatal Critical Care Review (NCCR) focusing on enhancing the experiences for families receiving neonatal care (NHS England 2019).

Occupational therapists receive dual training in the areas of physical and mental health. They are therefore uniquely placed to identify and support parents/caregivers who may be experiencing issues around psychological adjustment. Occupational therapists can support parents to develop successful psychological coping strategies and mediate the impact that parent mental health concerns may have on the development of parenting efficacy.

Parent support

22. **It is recommended** that occupational therapists support engagement in parenting occupations in the neonatal unit and following discharge (including, but not limited to, reading infant cues, guided participation in care, skin-to-skin, positive touch and holding) to promote decreased parent stress and positive improvements in parent–infant relationship and self-efficacy. 1A

(Evans et al 2014 [A]; Månsson et al 2019 [A]; Matricardi et al 2013 [B]; Melnyk et al 2006 [A]; Milgrom et al 2019 [A]; O'Brien et al 2018 [A]; Thomson et al 2020 [A]; White-Traut et al 2013 [A]; Zelkowitz et al 2011 [A]; Bäcke et al 2020 [C]; Nassef et al 2020 [C]; Suarez et al 2018 [C])
[New evidence 2022]

23. **It is recommended** that occupational therapists employ parent-focused interventions that incorporate parental attunement in order to reduce the psychosocial impact of delivering a high-risk infant, foster sensitive nurturing behaviour and promote the cognitive development of preterm infants. (Als et al 2003 [A]; Benzies et al 2013 [A]; Melnyk et al 2001 [A]; Nordhov et al 2010 [A]; Askary Kachoosangy et al 2020 [B]; Kraljevic and Warnock 2013 [B]) [New evidence 2022]	1A
24. **It is suggested** that occupational therapists engage parents in brief activity-based interventions during their infant's admission to the neonatal unit and that this can have a short-term effect in lowering parent anxiety. (Dür et al 2018 [B]; Mouradian et al 2013 [C]) [New evidence 2022]	2B
25. **It is recommended** that occupational therapists consider the use of e-health interventions (e.g. web-based platforms, mobile apps, video-conferencing etc.) to support parent engagement, particularly when parent presence may be interrupted. (Dol et al 2017 [A]) [New recommendation 2022]	1A
26. **It is recommended** that occupational therapists employ the use of parent-focused psychosocial interventions to decrease parent stress and anxiety and promote parent coping, confidence and early parent–infant relationships. (Kasparian et al 2019 [A]; Gramszlo et al 2020 [B]; Petteys and Adoumie 2018 [B]) [New recommendation 2022]	1A

5.9.2 Recommendation 22: Decreasing parent stress and promoting self-efficacy

Evans et al (2014) conducted a systematic review which aimed to investigate the efficacy of parent interventions in improving the quality of the relationships between mothers and preterm infants. The review included 14 individual randomised controlled trials.

A range of specific parent-support interventions were identified as having a positive effect on the maternal–infant relationship. These included: support by guided participation in their infant's caregiving; participating in skin-to-skin care with their infant, both throughout the neonatal unit admission and up to three months post-discharge; the provision of individualised family-based intervention during the neonatal unit admission; and the provision of home visits that focused on supporting parents with their infant's developing state regulation post-discharge up to 5 months of age. Although the variability in outcomes did not support deeper analysis to see whether intervention effects were greater in one set of interventions than another, all of the interventions that demonstrated effectiveness had common elements of supporting close, nurturing connections between parents and infants, supporting parents to read their infant's neurobehavioural state and respond sensitively, and actively engaging parents throughout their infant's neonatal unit admission.

A randomised controlled trial undertaken by **Matricardi et al (2013)** aimed to examine the effects of a parental intervention to reduce stress levels for mothers and fathers during

hospitalisation of very preterm infants. The study was conducted in Italy and involved 42 parents. The intervention focused on supporting parents to observe their infant's neurobehavioural cues, and to improve physical closeness between parents and their infant.

The stress scores of the parents who received the intervention showed a decrease (though not significant). Mothers demonstrated higher levels of stress than fathers, particularly in focusing on the alteration of their parental role. The intervention approach appeared effective in promoting parents' understanding of the behaviour of their infant, and gave parents a strengthened sense of their parental identity.

White-Traut et al's (2013) randomised controlled trial examined the impact of a specific parent-focused intervention, H-Hope (Hospital to Home: Optimizing the Infant's Environment), on mother and infant interaction patterns during feeding and play at 6 weeks' corrected age. The study was conducted in the United States and included 198 preterm infants and their mothers. The H-Hope intervention includes an infant-directed sensory programme, and a maternal-directed component focusing on education and social support through the provision of individualised participatory guidance during the hospital stay and post-discharge. The intervention began when the infants reached 32 weeks' postmenstrual age.

For the infant and mother dyads who received the intervention, there were slightly higher scores on the NCAST tool, which evaluates maternal–infant interaction during feeding (though these did not reach statistical significance). The level of mutuality observed between the infant and mother during play also demonstrated high responsivity for those who received the interventions when compared with those in the control group. The authors concluded that supporting maternal–infant interaction should be a key component in building a high-risk infant's capacity to engage in social interactions and promote development.

Melnyk et al (2006) conducted a randomised controlled trial which aimed to evaluate the efficacy of an educational-behavioural intervention programme which was designed to enhance parent–infant interactions and parent mental health outcomes. The Creating Opportunities for Parent Empowerment (COPE) programme is a four-phase programme that aims to provide parents with information on the appearance and behavioural characteristics of their infant to guide how parents can participate in their care, and incorporates activities that guide parents in implementing this new knowledge when caring for their infants. The study was conducted in the United States and included 260 parents or caregivers of preterm infants.

A range of positive outcomes was noted for the parents and infants who had received the COPE intervention. Length of admission to the neonatal unit was noted to be 3.8 days shorter than for those in the comparison group. Mothers in the COPE programme reported significantly less overall parental stress in the neonatal unit than mothers in the comparison group. There were no differences noted in fathers' reporting of stress. Mothers and fathers in the COPE programme reported significantly higher parental beliefs about their role, and what characteristics and behaviours to expect from their preterm infants. Both mothers and fathers also demonstrated more positive parenting interactions with their infants during the neonatal admission. By 2 months' corrected age, mothers who had received the COPE intervention reported significantly less anxiety and fewer symptoms of depression than mothers in the comparison group.

A randomised controlled trial carried out by **Zelkowitz et al (2011)** aimed to determine the effect of a brief skills-based intervention on the anxiety of mothers of very low birthweight (VLBW) infants. The Cues Programme is an intervention designed to reduce anxiety and develop sensitive interaction skills for mothers of VLBW infants. It is a brief intervention delivered over six sessions of 45–75 minutes in length. The intervention included educating mothers on strategies to reduce feelings of anxiety, and recognising and interpreting their infants' cues to respond with sensitivity. Mothers in the comparison group also received six direct contacts from a researcher who provided them with information on standard infant care information (e.g. immunisations, safety). The study was conducted in Canada and included 121 infant–mother dyads.

Both groups of mothers demonstrated significant reductions in their experience of anxiety immediately following the intervention period. Their experiences of stress were similar, and both groups of mothers were equally sensitive in their interaction with their infants. The authors concluded that while no key differences were found between the intervention and comparison groups, the key factor may have been the availability of a supportive practitioner who was proactive in reaching out to mothers, providing information and reassurance.

Milgrom et al (2019) conducted a randomised controlled trial to evaluate a parent sensitivity intervention (based on a Mother–Infant Transaction Program (MITP) approach) in terms of neurobehavioural development to preschool age. One hundred and twenty-three very and extremely preterm infants were allocated to the parent sensitivity intervention (called PremieStart) or standard care. Child outcomes were assessed at 2 and 4.5 years of age. The PremieStart intervention involved nine weekly sessions delivered in the NICU followed by a home-booster session one month post-discharge. Components of the intervention included recognising infant cues, quality of motor behaviours, provision of graded stimulation, touch, movement and massage, kangaroo care and multisensory stimulation. The study results indicated no significant between-group differences in behaviour concerns at 2 or 4.5 years, general development at 2 years, or cognitive and executive functioning at 4.5 years. The authors concluded that the quality of standard NICU care may now have advanced to the point where MITP-type interventions have limited additional impact on infant long-term neurobehavioural outcomes.

Månsson et al (2019) conducted a quasi-experimental study to evaluate the impact on parent stress of an individualised neonatal parent support programme. Parents of preterm infants were consecutively assigned to standard care (n=130) and an intervention group (n=101). The intervention comprised of a parent support programme which focused on supportive parent-centred communication based on the parent's needs and revolved around four individual nurse–parent dialogues used during the infant's admission to the NICU. The results of the study indicated that parent stress (as measured by the PSS:NICU) did not vary significantly between the control and intervention groups for either mothers or fathers. Differences at item level were noted, with lower stress recorded in the intervention-group mothers in relation to other sick babies being cared for in the same room, unusual/abnormal breathing patterns, being able to hold their baby, forgetting what their baby looked like, being afraid of holding/touching the baby, and feeling that the staff were closer to the baby than the parent was.

Thomson et al (2020) conducted a meta-ethnographic systematic review to identify what facilitates and enables parents' experiences of emotional closeness to their infants while cared for in a neonatal unit. The review incorporated 34 studies from 17 countries. Three overarching themes were identified. These were: (a) embodied connections (describing how emotional closeness was facilitated by reciprocal parent–infant interactions, spending

time as a family, and methods for parents to feel connected while physically separated); (b) inner knowing (describing how knowledge about infant and maternal health and understanding the norms of neonatal care facilitated emotional closeness); and (c) evolving parental role (described as how emotional closeness was intertwined with parental identities of contributing to their infant's health, providing direct care and being acknowledged as a parent). The findings showed that parent–infant closeness evolves and is enabled by multifaceted biopsychosocial factors. The authors conclude that strategies to promote parent–infant closeness may include the creation of private and uninterrupted family time, parent strategies to remain emotionally connected to their baby even when geographically separated, and education regarding neurobiological development for staff.

Suarez et al (2018) conducted a narrative-based qualitative study to provide insight into the experience of becoming a mother for women in opiate recovery. Four mothers who were participating in an opiate substance abuse recovery programme and whose infant was born with neonatal abstinence syndrome were interviewed for the study. The themes which emerged included: (a) a deep love of being a mother, and the baby as a key motivator for sobriety; (b) the determination to make the relationship between mother and child different from the one the mother had experienced with her own mother; (c) difficulty with understanding child development as it unfolded; and (d) mixed reviews of the healthcare experience. The authors conclude that the core principles of occupational therapy have a key role in supporting mothers in substance misuse recovery and their babies born with NAS. These professional attributes include the development of therapeutic relationships, in-depth knowledge of typical development, and expertise in co-regulation using relationship and sensory-based strategies to support the mother–infant relationship.

As described in Sections 5.8.2 and 5.8.3, **O'Brien et al (2018)** conducted a multi-centre randomised controlled trial which included 26 neonatal units in Canada, Australia and New Zealand to analyse the effect of the Family Integrated Care (FICare) programme on infant and parent outcomes, safety and resource use. As part of the programme of psychosocial support, parents were provided with emotional support, coping strategies, stress-reducing activities, and other assistance through informal peer-to-peer support and veteran parent and social work involvement in the education sessions. As outlined in the previous sections, the results of the trial included lower mean stress and anxiety scores for parents participating in the FICare intervention.

Bäcke et al (2020) explored the experiences of parents whose infants were receiving therapeutic hypothermia (TH) after severe perinatal asphyxia, in relation to their experience of closeness and involvement in their infant's care while in the NICU. Semi-structured interviews were completed with 11 parents. The findings revealed three overarching themes which explained parent experiences: parenting role (including participation, emotional chaos and being close); support in a chaotic situation (including the need for information, emotional support and ambivalent emotions); and the environment (including barriers to closeness and supporting presence). The authors concluded that parents of infants receiving TH want to be closer to and more actively involved in the care of their infants but can find it difficult to take the initiative themselves. More active guidance by NICU staff may be one way to promote parental closeness and participation during TH.

Further evidence in relation to the specific experiences of parents whose infants receive therapeutic hypothermia (TH) in the neonatal unit is provided by **Nassef et al (2020)**. This qualitative descriptive study with 14 parents (of seven infants) explored their experiences of TH in their newborn infant suffering from hypoxic ischaemic encephalopathy following

perinatal asphyxia. Findings identified an overall theme of 'transition through a life-altering time' which was supported by three sub-themes: (a) trepidation about prognosis, (b) transitioning into parenthood supported by the caring philosophy of family-centred care (FCC), and (c) rewarming as a milestone. The authors concluded that parent experiences of TH are based on the immediate emotions and stress of uncertainty of the infant's prognosis. They contend that the values embodied in family-centred care support a natural transitioning into parenthood by enabling parental involvement in nursing care and decisions.

Evidence overview

The evidence that supports the relationship between supporting parent engagement in parenting occupations (decreases in parent stress and improvements in parent–infant relationship) and parent self-efficacy is strong. Although there is some inconsistency across the findings of individual studies, it is clear that an approach that includes parent-directed interventions and engagement is a key attribute of success. Further evidence is now shaping our understanding of supporting parenting occupations in specific subsets of parents (e.g. those with infants with NAS and who have received TH). The evidence for this recommendation is drawn from two systematic reviews, five randomised controlled trials which are of high quality, and a further randomised controlled trial of moderate quality, one quasi-experimental trial and three qualitative studies.

Supporting parent engagement in parenting occupation-based activity has been demonstrated as an effective way to decrease parent stress, promote positive improvements in parent–infant relationship and support parents to feel that they are contributing to their infants' care. Such activities can include learning to read and respond to infant cues, guided participation in caregiving, skin-to-skin care and positive touch.

5.9.3 Recommendation 23: Supporting maternal/parental sensitivity

Benzies et al (2013) conducted a systematic review which reviewed early interventions aimed at promoting parent outcomes and identified the key components associated with maternal and child outcomes. The review incorporated 18 individual studies with study sample sizes ranging from 23 to 985 parents. There was a broad geographical representation, including studies from Australia, England, Germany, Italy, Japan, the Netherlands, Norway and the United States.

Eleven of the included studies reported maternal outcomes of stress, anxiety, depression, self-efficacy and sensitivity/responsiveness in infant interactions. Positive and clinically meaningful effects were demonstrated for the reduction of symptoms of depression and anxiety, and the promotion of parent self-efficacy. Interventions that included a specific element of psychosocial support resulted in improved outcomes for mothers. In four studies that included a component of maternal psychosocial support, improved infant outcomes were also reported.

A systematic review conducted by **Kraljevic and Warnock (2013)** set out to assess how effective early informational and behavioural interventions are in reducing the incidence of maternal anxiety, depression, stress, parenting stress and symptoms of post-traumatic stress disorder (PTSD) for mothers who experience psychological trauma associated with preterm birth. The review included eight individual studies, which collectively involved 1,005 mothers. Interventions were diverse, but used an educational and/or a behavioural approach to support mothers. Maternal sensitivity training (to infant cues) was a component of the majority of the study interventions.

The findings of the review confirmed that mothers often experience early onset of significant depression, anxiety, parenting stress and symptoms of acute stress disorder during their infant's admission to the neonatal unit. There were inconsistent outcomes across the studies in terms of their efficacy in reducing maternal psychological symptoms – half of the reviewed programmes had a positive impact on one to three psychological outcomes. As a result of this variability of the interventions, the authors were unable to draw conclusions regarding the overall effect. However, while the outcomes of specific interventions were inconsistent, this is an important review in highlighting the early presentation of psychological distress of mothers of preterm infants, and suggests that parent wellbeing should be a key consideration in neonatal caregiving approaches.

Nordhov et al (2010) conducted a randomised controlled trial to analyse whether the Mother–Infant Transaction Program (MITP) led to more nurturing child-rearing attitudes. The study was conducted in Norway and included 146 preterm or low birthweight infants. The intervention comprised a daily one-hour session, delivered for seven consecutive days. The aim of the intervention was to enable parents to appreciate and recognise their infant's unique characteristics, temperament and developmental potential, with a specific focus on the infant's cues, especially those signalling stimulus overload, distress and readiness for interaction, in order to optimise parent–infant interaction and play.

Using a questionnaire that assessed maternal attitudes around child-rearing, mothers in the intervention group reported significantly greater nurturing attitudes when their children were 12 and 24 months of age. However, it was also noted that there were changes in maternal attitudes across mothers of both term and preterm infants over time, indicating that changes in child-rearing attitudes also develop independently of early intervention and birth history.

In a randomised controlled trial undertaken by **Melnyk et al (2001)**, the researchers aimed to evaluate the Creating Opportunities for Parent Empowerment (COPE) programme in terms of maternal coping and infant cognitive development. The study was conducted in the United States and included 42 mothers of preterm infants. The COPE intervention commenced two to four days following the infant's birth and continued to one week post-discharge.

The COPE intervention was demonstrated to result in significantly higher mental development scores (as measured by the Bayley Scales of Infant Development) at 3 months' corrected age, compared with the infants in the comparison group. This difference was noted to have widened further by the time the infants were 6 months' corrected age. In relation to the experience of parent stress, mothers who had participated in the COPE programme were reported to be significantly less stressed by the sights and sounds of the neonatal unit environment than the mothers in the comparison group, and held significantly stronger beliefs about what behaviours and characteristics to expect from their preterm infants.

Askary Kachoosangy et al (2020) completed a randomised controlled trial which evaluated the effectiveness of the Creating Opportunities for Parent Empowerment (COPE) programme for the perceived maternal parenting self-efficacy of parents of preterm infants. The study included 45 preterm infants who were randomly allocated to treatment, supervision and control groups. Families in the treatment and supervision groups both received the COPE intervention. The intervention was delivered in four phases covering from two to four days after birth to one week post-discharge. Data was analysed one month post-discharge. The results indicated that families who received the COPE intervention had significantly higher self-efficacy scores than those in the control group.

Finally, the randomised controlled trial conducted by **Als et al (2003)** which, as previously described, included 92 infants drawn from three neonatal units in the United States, tested the effectiveness of individualised developmental care. Infants in the experimental group received the NIDCAP intervention, with the infants in the control group receiving standard care. Outcomes related to medical status, developmental status and parent functioning were measured at 2 weeks' corrected age. Parents of infants supported by the NIDCAP approach perceived their infants as having improved regulation. They also experienced enhancements in their own parental competence, with a corresponding reduction in stress experiences.

Evidence overview

The evidence supporting the relationship between the provision of parent-focused interventions incorporating maternal sensitivity elements and the experience of psychosocial impacts resulting from the delivery of a high-risk infant is strong. Providing parent-focused interventions that incorporate strategies to support the development of parent sensitivity has also been demonstrated as an effective way to reduce psychosocial impacts (such as anxiety and depression) of the birth of a high-risk infant on parents and foster sensitive nurturing behaviour. These types of interventions have also been demonstrated to promote the cognitive development of preterm infants. This recommendation is supported by one systematic review and three randomised controlled trials of high quality, one randomised controlled trial of moderate quality and a further systematic review of moderate quality.

5.9.4 Recommendation 24: Interventions to decrease parent anxiety

Dür et al (2018) conducted a qualitative study to explore meaningful activities of parents of very low birthweight (VLBW) preterm infants aimed at understanding their clinical relevance and how they may be used in neonatal practice. Thirty-six parents participated in focus groups. The findings indicated activity-related themes which were found to be important to parents of VLBW preterm infants: a change in the meaning of their activities; a transition from a feeling of parental immaturity to a feeling of maturity; from following healthcare instructions to possessing healthcare skills; and a transition from a functioning-only state to a balance of activities. This last theme focused on the importance of regaining an occupational balance of activities that had meaning to the participants, such as engaging in gardening, favoured leisure activities (e.g. video games, engaging in amateur theatre, taking time for a coffee outside of the hospital etc.).

Mouradian et al (2013) conducted a mixed-methods quasi-experimental study which aimed to reduce parent stress in the neonatal unit through participation in an art-based occupation group. The intervention consisted of a weekly group of two hours in length which ran consecutively over a five-month period. Any parents whose infants were admitted to the neonatal unit during that time were invited to participate. The group was based around an art activity (scrapbooking). This activity was selected due to the long history in the use of expressive arts by occupational therapists and its link to creativity, a fundamental element of occupational therapy practice. The study was conducted in the United States and included 45 parents.

Parents completed an anxiety measure before and after their participation in the group activity. There was noted to be a statistically significant reduction in state anxiety for the participants, which linked to a clinically significant reduction in anxiety symptoms in approximately 25% of parents.

Evidence overview

Providing opportunities for parents to engage in meaningful occupation-based activity has been demonstrated as an effective way to achieve short-term stress reduction and leads to a greater sense of occupational balance and wellbeing.

This has been included as a conditional suggestion as it is recognised that the availability of occupational therapy services in the UK and resources across neonatal units may influence the process of implementing this suggestion in practice. However, it contributes to an overall recommendation that occupational therapists utilise an occupation-based framework for practice in the neonatal unit that, in addition to supporting the development of the infant, also works to support sensitive and appropriate parent engagement in caregiving. The evidence for this suggestion is drawn from one quasi-experimental study and one qualitative study.

5.9.5 Recommendation 25: Use of e-health interventions

Dol et al (2017) conducted a systematic review to examine the effects of e-health interventions used in neonatal intensive care units on parent-related and infant outcomes. Eight studies of varying design were included in the review. Studies were noted to be of low or very low quality. The heterogeneity of the study designs and small sample sizes meant that meta-analysis of the pooled data could not be conducted. The findings suggested parent acceptance and use of e-health technologies, but there was an unclear impact in relation to infant outcomes, including length of hospital admission. Trends were also noted in relation to reduction of parent anxiety and stress. No significant differences were found in any of the studies. The authors concluded that given the consistency of findings with regards to parent acceptance, the incorporation and evaluation of e-health interventions in the NICU setting is warranted. However, further high-level studies with larger sample sizes are needed to detect changes in parent and infant outcomes.

The review outlined above noted that half of the included studies were published in the previous two-year period, suggesting this is a growing area of technology development and evaluation. The use of e-health technologies increased further during 2020–2021 as alternative means of enabling parents to retain a sense of connection to their infant even when circumstances meant that parent presence on the neonatal unit was interrupted. Occupational therapists can contribute to the neonatal multidisciplinary approach in the selection and review and/or development of e-health approaches that are supportive of the infant and family needs specific to their unit and local population.

Evidence overview

There is high-quality evidence (systematic review) that the provision of e-health interventions in the neonatal setting is gaining traction, with consistent evidence for parent use and acceptability as part of overall neonatal care provision. However, it should be noted that the individual studies included in the review were of low quality and that to date there is no conclusive evidence on the efficacy of e-health technologies in relation to improving infant and parent outcomes. While trends indicate potential benefits of e-health in relation to parent stress and anxiety, these require further research. The evidence for this recommendation is drawn from one high-level systematic review.

5.9.6 Recommendation 26: Use of parent-focused psychosocial interventions

Kasparian et al (2019) conducted a systematic review on the efficacy and cost-effectiveness of mental health interventions delivered in neonatal, paediatric or cardiac intensive care units for parents of infants with congenital heart disease. Five controlled trials were included in the review. All of the interventions included in the original studies involved face-to-face parent delivery but had varying therapeutic approaches, including parent–infant relationship, early palliative care, psycho-education strategies, parenting skills training and family-centred nursing interventions. Four of the five trials demonstrated a reduction in maternal anxiety, though the quality of each of the papers was considered to be low. Positive results were also reported in relation to maternal coping, mother–infant attachment, parenting confidence and satisfaction with clinical care, and infant mental development at 6 months. Mixed results were found for maternal depression and infant feeding and no evidence of efficacy was found for improving parent, infant or family quality of life, physical health or reduction in length of infant hospital stay. The authors concluded that the existing evidence base provides preliminary support for the efficacy of psychological interventions in reducing parent anxiety and improving parent coping, confidence and early parent–infant relationships. Further research is required to strengthen the evidence base and develop robust practice recommendations.

Gramszlo et al (2020) conducted a qualitative study to identify parent preferences for the goals and structure of intervention programmes designed to support the psychosocial needs of families impacted by congenital heart disease. Semi-structured interviews were conducted with 34 parents of infants who had undergone surgery at <6 months of age. Six broad themes were identified: supporting parents to partner in their child's hospital care; promotion of parental self-care and stress management; facilitation of effective communication between parents and providers; preparing parents for common challenges after hospitalisation; education for parents about neurodevelopment; and helping parents to engage effective social support. Parents also provided insight into the preferred structure of psychosocial interventions and this included: offering formalised support at each stage of the infant's emerging care, developing brief (2–3 sessions) psychosocial intervention models, providing in-person individualised or small-group support, and engaging multidisciplinary providers and peer mentors to provide psychosocial support. The authors concluded that formalised, individualised and ongoing psychosocial care may help reduce stress and mitigate the impact of parent anxiety and depression on child outcomes.

Petteys and Adoumie (2018) conducted a pilot of a randomised controlled trial to examine the impact of parent education and participation in mindfulness-based neurodevelopmental care on parent outcomes such as stress, bonding and satisfaction, in addition to infant length of stay in the NICU. The study recruited a convenience sample of 55 parent–infant dyads who were randomly allocated to an intervention or control group. Infants were born at <35 weeks' gestation and had an expected admission of >14 days. Parents in the intervention group participated in a one-on-one educational session of 30–60 minutes' duration that taught mindfulness techniques and structured neurodevelopmental care training activities. An education packet was also provided to parents for further reference. Mindfulness techniques education included focused breathing, personal awareness and non-judgement, and awareness and non-judgement of their infant. Neurodevelopmental care training centred on observation and recognition of infant cues, signs of organised/disorganised physiological, motor and state behaviours, and development of infant self-regulation.

Findings indicated no statistically significant differences in parent outcomes between the two groups. However, the experimental group demonstrated a significant reduction in stress

scores from enrolment to discharge. Infants in the intervention group also showed a significantly shorter length of hospital admission than those in the control group.

Evidence overview
There is low–moderate evidence that providing parent-focused psychosocial interventions can support parents in their experience of stress, anxiety, coping, and the development of early parent–infant relationships during an admission of their baby to a neonatal unit. Two of the three studies above were conducted with a cohort of parents of infants with congenital heart disease and so care needs to be taken in relation to the generalisability and transferability of the results to the broader neonatal population. The evidence for this suggestion is drawn from one systematic review, one pilot RCT and one qualitative study.

The training of occupational therapists in both physical and mental health means that they are well placed to contribute to the provision of psychosocial support for families whose infants are being cared for in a neonatal unit as part of a broader multidisciplinary team approach. Working collaboratively with specialist staff (e.g. psychologists), occupational therapists can employ appropriate psychosocial approaches to support parent adjustment to becoming a parent of a high-risk infant and enable their participation in activities they consider meaningful to being a parent. The use of specific psychosocial techniques (e.g. mindfulness etc.) should only be incorporated by occupational therapists who have additional post-graduate training in such interventions.

5.10 Identifying developmental concerns

5.10.1 Introduction

A large body of research has highlighted the impact of the increase in survival of infants born prematurely and provided clarity around the range of neurodevelopmental issues with which preterm infants commonly present. The presentation of ex-preterm infants with subsequent developmental concerns provides a strong impetus for occupational therapy prevention and early intervention for preterm infants.

Specific concerns attributable to gestational age include:

- Extremely preterm infants (22–26 weeks' gestation): serious cognitive impairment impacting on 40% of ex-preterm infants in comparison with 1.3% of controls; identification of cerebral palsy in 17% of ex-preterm infants; impairments in motor planning, visuo-spatial, sensorimotor and attention functions (Johnson et al 2009, Marlow et al 2007).

- Very preterm infants (born before 33 weeks' gestation): 32% had a moderate cognitive impairment and 12% had a severe cognitive impairment; overall disability (a variable composed of neuromotor and neurosensory impairment) was identified as severe in 5% of children, moderate in 9% of children and mild in 25% of children; parents of ex-preterm infants were twice as likely to report behavioural issues in their children compared with full-term controls in relation to increased activity/inattention, increased emotional lability and issues with peer relationships (Larroque et al 2008, Delobel-Ayoub et al 2009).

- Moderate to late preterm infants (32–36 weeks' gestation): increased incidence of autism spectrum disorders, neurosensory impairment, cognitive impairment and delayed social-emotional competence (Johnson et al 2014, Guy et al 2015).

Infants born at term who experience complications, such as post-asphyxia hypoxic ischaemic neonatal encephalopathy, also require ongoing developmental support and monitoring. The proportion of infants experiencing adverse events (neonatal death, cerebral palsy or motor/cognitive impairment) is 47%, of which 44% were in evidence prior to 3 years of age (Pin et al 2009). Additionally, children without presentations of severe developmental outcomes initially were subsequently identified as experiencing subtle deficits such as learning difficulties and visual-perceptual difficulties (Pin et al 2009).

Ensuring early identification of any emerging developmental concerns, and subsequent referral to relevant early intervention services, is imperative to optimise infant motor and cognitive plasticity, prevent secondary complications and enhance caregiver wellbeing (Novak et al 2020). This will include screening and assessment for developmental concerns across a range of performance domains (e.g. cognitive, motor and sensory) to promote the infant/child's engagement in age-appropriate activities of daily living.

Occupational therapists are concerned with occupational performance – that is, the dynamic relationship between a person, a person's environment, and their occupations. Occupational therapists can screen or assess for areas of concern across a range of performance domains (cognitive, sensory processing and functional movement skills) and consider the impact this has on the infant/child's developmental progression. Equally, they address the constraining and enabling factors that the environment may have on the child's performance and how attributes in their environment may also be enhanced to promote acquisition of developmental goals.

Identifying developmental concerns

27. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to cognitive performance and social interaction, to support the development of the infant's occupations, with referral to early intervention services as indicated. (Maitra et al 2014 [A]; Magill-Evans et al 2002 [C]; Pineda et al 2015 [C]; Sajaniemi et al 2001 [C])	1A
28. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to functional motor skills, to support the development of the infant's occupations, with referral to early intervention services as indicated. (Maitra et al 2014 [A]; Bigsby et al 2011 [B]; Watkins et al 2014 [C]; Fewell and Claussen 2000 [C])	1A
29. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to sensory processing difficulties, in order to support the development of the infant's occupations, with referral for early intervention services as indicated. (Bröring et al 2017 [A]; Witt Mitchell et al 2015 [B]; Crozier et al 2016 [C]) [New evidence 2022]	1A

5.10.2 Recommendation 27: Cognition and social interaction

Maitra et al (2014) conducted a systematic review which aimed to determine whether low birthweight (LBW) or preterm birth led to difficulties in mental, neuro-musculoskeletal and movement-related tasks at school age. Child outcomes of interest were IQ, attention, executive function, emotional-behavioural characteristics, academic skills, visual-motor function, visual-perceptual function, hand skills, sensory-motor performance, and motor co-ordination and control. The review included 40 individual studies, including 6,553 children born LBW or preterm and 24,624 typically developing children.

Following a meta-analysis it was identified that children born with LBW demonstrated considerable difficulties in mental functions compared with children of normal birthweight. Children born preterm also demonstrated significant difficulties in mental functions compared with term-born peers. Children born with LBW or preterm made more mental function errors, took longer during decision-making tasks and received lower scores on mental function assessments than their typically developing counterparts. The study also demonstrates a strong link between cognitive difficulties and problems with motor performance in preterm and LBW infants. Based on the work of Spencer et al (2008), the review authors suggest that children born either LBW or preterm were associated with reduced grey matter density in the temporal brain structures that continued into childhood, and that this atypical brain structure and associated cortical dysfunction within the temporal lobe may result in poor cognitive functioning, because of the important role that temporal lobe structures play in relation to memory, language and learning.

In a longitudinal observational study undertaken by **Magill-Evans et al (2002)**, the researchers aimed to compare the cognitive and language development of children at 10 years of age born preterm with those born at term. The children were assessed using an IQ and language scale. The study was conducted in Canada and included 43 children.

The children born preterm were identified with subtle delays. They demonstrated a significantly lower performance on the performance scale of the Wechsler Intelligence Scale for Children (WISC-III), and on the language scale. In relation to the IQ performance scale, children appeared to have most difficulty with items requiring visual-spatial skills.

Pineda et al (2015) conducted a cohort study which aimed to assess whether neonatal social characteristics are related to risk of autism at 2 years' corrected age. The study included 62 infants who had been born at <30 weeks' gestation. The infants were assessed at term-equivalent age, prior to their discharge from the neonatal unit, using the NICU Network Neurobehavioral Scale. They were re-assessed at 2 years of age using the Bayley Scales of Infant and Toddler Development and the Modified Checklist for Autism in Toddlers. The study was conducted in the United States.

The researchers were trying to ascertain whether there were infant behaviours in the neonatal period that may be linked to later presentations of autism. However, atypical social interactions in infancy were not observed among infants who later screened positive for autism risk. Instead, some of the items (gaze aversion and endpoint nystagmus) were linked with better developmental outcomes.

Sajaniemi et al's (2001) cohort study aimed to assess whether occupational therapy intervention affected cognitive skills and attachment patterns for infants born with extremely low birthweights. The intervention involved weekly occupational therapy sessions of 60 minutes in length when the infants were between 6 and 12 months of age. The focus of the intervention was to educate parents on adaptation of the sensory environment,

interventions to support sensory modulation difficulties, and facilitation of handling to promote sensory-motor development. Follow-up assessment was carried out when the infants were 2 and 4 years of age. The study was conducted in Finland and included 115 infants.

Overall, infants who had received the intervention demonstrated significantly higher cognitive scores (as measured by the Wechsler Preschool and Primary Scale of Intelligence – WPPSI) at 4 years of age than those in the control group. At 2 years of age, the risk factor and cognitive scores were significantly lower for boys. By 4 years of age, boys in the intervention group were demonstrating better verbal performance than those in the control group. Finally, evaluation of the parent–child attachment demonstrated significantly different patterns of attachment between the intervention and control groups, with the intervention group demonstrating more normative patterns. This particular study highlights the positive effect that early intervention for an at-risk population may promote in relation to cognitive development and parent–infant attachment.

Evidence overview

A number of studies have been undertaken to explore the impact of the birth of a high-risk infant on later cognitive and social interaction function. The studies, while not all high quality, have consistently identified an association between high-risk infants and later cognitive and social-emotional functions that are important in the performance of childhood occupations.

It is recommended that occupational therapists routinely provide screening and assessment of high-risk infants in this area in order to support the development of infant occupations, and/or provide referral to early intervention services as needed.

The evidence for this recommendation is drawn from one high-level and three low-level quality studies.

Occupational therapy plays an important role in the assessment and management of cognitive/learning difficulties (e.g. IQ, attention, executive function, emotional-behavioural characteristics and academic areas such as spelling, reading and mathematics) in order to maximise a child's potential. They can provide a key contribution to the early identification of performance concerns in these domains and ensure timely referral for targeted early intervention support.

5.10.3 Recommendation 28: Functional motor skills

The systematic review conducted by **Maitra et al (2014)**, as described earlier, identified following a meta-analysis that children born with low birthweight demonstrated significant difficulties with neuro-musculoskeletal and movement-related tasks when compared with children of normal birthweight. Similarly, children born preterm also demonstrated considerable difficulties with neuro-musculoskeletal and movement-related tasks compared with their term-born peers. Children born LBW or preterm made more neuro-musculoskeletal and movement-related errors, took more time to complete tasks and received lower scores on neuro-musculoskeletal and movement-related assessments than their typically developing counterparts.

In a cohort study conducted by **Bigsby et al (2011)**, the researchers aimed to compare the quality of movement of infants born preterm (<33 weeks' gestation), who had experienced prenatal cocaine exposure at 4 months' corrected age, with that of unexposed preterm infants using the Posture and Fine Motor Assessment of Infants. The study was conducted in the United States and included 903 infants.

It was identified that infants prenatally exposed to cocaine had significantly lower posture scores than infants in the unexposed group. There were no main effects noted of cocaine exposure on the performance of fine motor skills at 4 months of age. Gestational age at birth had an independent effect on both posture and fine motor performance at 4 months' corrected age.

Watkins et al (2014) conducted a retrospective analysis of cohort data in order to investigate the association between receiving occupational therapy and physiotherapy services between 9 months and 2 years of age, and preschool motor performance. The study included 500 VLBW children, born in the United States, who had received therapy services. Functional motor skills were evaluated using an early screening inventory, the Bruininks–Oseretsky Test of Motor Proficiency, and the Movement Assessment Battery for Children.

Children born with VLBW who had received physiotherapy and occupational therapy services between 9 and 24 months were more likely to show improved performance on motor items that require complex motor planning at preschool age (e.g. skipping, walking backwards etc.) compared with children who had not received the intervention, though this difference was not statistically significant.

In a cohort study conducted by **Fewell and Claussen (2000)**, the researchers aimed to use developmental milestone data to report developmental fine and gross motor trajectories over the first two years of life, to identify whether maternal cocaine use has short- or long-term harmful effects on motor skills. The study was conducted in the United States and included 73 children with assessments conducted at 6, 12, 18 and 24 months of age. The average gestational age at birth for the infants was 38.3 weeks. Infant fine and gross motor skills were assessed using the Peabody Developmental Motor Scales.

Fine and gross motor skills scores were below the normative scales of the assessment for children prenatally exposed to cocaine. The difference between children's scores from the normative scores increased over time, with fine motor skills showing a greater decrease in performance compared with gross motor skills.

Evidence overview

A number of studies have been undertaken to explore the impact of the birth of a high-risk infant on functional motor outcomes. The studies vary in quality but identify an association between high-risk infants and functional motor skills that are important in the performance of childhood occupations.

It is recommended that occupational therapists routinely provide screening and assessment of high-risk infants in this area in order to support the development of infant occupations, and/or provide referral to early intervention services as needed. The evidence for this recommendation is drawn from one high-level, one moderate-level and two low-level evidence sources.

Occupational therapy plays an important role in the assessment and management of motor skills, particularly in relation to posture and fine motor functions that are key to performance of preschool and school occupations. Occupational therapists can provide a key contribution to the early identification of performance concerns in these domains and ensure timely referral for targeted early intervention support.

5.10.4 Recommendation 29: Sensory processing

Witt Mitchell et al (2015) conducted a systematic review which aimed to explore the prevalence and type of sensory processing disorders in children aged birth to 3 years who had been born preterm. The review included 45 individual studies which collectively involved 2,584 children.

Sensory processing dysfunction has the potential to influence the development of play, social participation, education, and self-care occupations. Sensory processing dysfunction is an umbrella term which includes sensory modulation disorder (SMD), sensory discrimination disorder (SDD) and sensory-based motor disorder (SBMD).

Witt Mitchell et al (2015) describe these categories as:

- Sensory modulation disorder: a mismatch between the demands of the environment and a person's emotional and attentional responses based on the ability of the central nervous system to effectively alter neural messages from sensory input. Sensory modulation disorder consists of three sub-types: sensory over-responsivity, sensory under-responsivity and sensory seeking.
- Sensory discrimination disorder: the inability to interpret qualities of sensory stimuli, such as the location of stimuli or similarities and differences between stimuli.
- Sensory-based motor disorder: postural instability or deficits in voluntary movement caused by problems processing sensory input in one or more sensory systems.

A substantive proportion of the findings from the individual studies suggested that children born preterm may be at risk for sensory processing dysfunctions. Evidence of sensory modulation disorders, particularly sensory over-responsivity, was most prominent.

Bröring et al (2017) completed a systematic review on sensory modulation problems in preterm infants and children (born at <37 weeks' gestation) and their association with neurocognitive and behavioural problems. The review incorporated 18 studies. The review indicated that most studies provided evidence of sensory modulation problems in preterm infants. In exploring risk factors for sensory modulation problems, earlier gestational age at

birth, white and grey matter brain abnormalities and length of NICU admission were identified. Seven of the studies explored correlation between sensory modulation and cognitive development, of which five studies identified that there was not a significant association. Five studies explored the relationship between sensory modulation and behavioural functioning. Two studies showed coinciding diagnoses of sensory modulation difficulties with autism spectrum disorder, and three found associations with regulatory issues, including fearful and less soothable temperaments.

A cohort study conducted by **Crozier et al (2016)** also aimed to examine the prevalence and type of sensory processing differences in children born preterm and understand the risk factors for atypical sensory processing difficulties. The study was conducted in Canada and included 160 children who had been born at <25 weeks' gestation and <800 grams. Assessment was conducted in a follow-up clinic when the children were 4.5 years of age.

Forty-six per cent of the children in the cohort presented with atypical sensory processing patterns. In contrast to Witt Mitchell et al (2015), the majority of infants in this study (40%) demonstrated greater under-responsiveness or sensory seeking (high threshold for sensory stimulation). Approximately one-third of children demonstrated a low threshold for visual, auditory, chemosensory, movement and tactile sensory input.

Evidence overview

Three studies have been undertaken to explore the impact of the birth of a high-risk infant on the development of atypical sensory processing performance. The studies clearly identify an association between high-risk infants and sensory processing difficulties that may influence the development of play, social participation, education, and self-care occupations.

It is recommended that occupational therapists routinely provide screening and assessment of high-risk infants in this area in order to support the development of infant occupations, and/or provide referral to early intervention services as needed. The evidence for this recommendation is supported by two moderate-level systematic reviews and one low-level cohort study.

Occupational therapy plays an important role in the assessment and management of sensory processing skills, particularly in supporting children and families to develop strategies that support their sensory processing patterns and optimise their engagement in childhood occupations. Occupational therapists can provide a key contribution to the early identification of performance concerns in these domains and ensure timely referral for targeted early intervention support.

5.11 Early intervention

5.11.1 Introduction

Infants who are considered high risk as a result of prematurity or other health factors may experience ongoing developmental concerns that can impact their participation in infant and child occupations. Early intervention (EI) services encompass a range of services designed to provide therapeutic interventions and family support that promote optimal development for the infant and their family.

In its most comprehensive form, early intervention 'enables every infant, child and young person to acquire the social and emotional foundations upon which our success as human beings depends' (Allen 2011, p3). The term early intervention does not constitute a single programme but refers to different packages of services that may vary within and across

localities with regard to service delivery models and the professional disciplines involved (McManus et al 2013). Hutchon et al (2019) highlighted within their review a summary of the key components for inclusion in early intervention programmes, e.g. play which is developmentally apt and intrinsically motivating; a focus on parent–infant relationships and regulation; supporting parent–infant communication responsivity; and parental wellbeing.

Early experiences will influence the developing architecture of a child's brain, and it is therefore imperative that maximum opportunities are provided to high-risk infants and their families to engage in experiences that will promote their future cognitive, physical and social-emotional development. Early identification of need, appropriate referral and intervention are therefore of high importance (Novak et al 2020).

In the UK, developmental follow-up services are usually provided for infants who have experienced a neonatal unit admission and are considered to be at risk for emerging or ongoing developmental concerns. In many areas, occupational therapists are included within multidisciplinary teams providing formal developmental follow-up services using screening, assessment, and consultation and referral advice. Further information and guidance for the provision of developmental follow-up services for preterm babies can be obtained in the NICE guidance (NICE 2018).

For the purposes of this guideline, early intervention occupational therapy services will refer to a variety of service models provided by neonatal and paediatric occupational therapists which aim to promote child development across all relevant domains to support the child's and family's participation in meaningful occupations.

Occupational therapy early intervention services may be provided in hospitals (outpatient settings), community settings (e.g. child development centres) and in the family's home environment. Intervention can be provided on a one-to-one basis, in group settings or by using a consultation/advice model.

Early intervention

30. **It is recommended** that occupational therapists provide early developmental intervention programmes for preterm infants to promote improved cognitive performance through the preschool years. (Orton et al 2009 [A]; Spittle et al 2015 [A]; Spittle et al 2007 [A])	1A
31. **It is recommended** that occupational therapists provide home-based early intervention programmes for infants born at <30 weeks' gestation in the first year of life as this may result in decreasing parent anxiety. (Spencer-Smith et al 2012 [A])	1A
32. **It is recommended** that occupational therapists facilitate individualised functional motor interventions for high-risk infants and young children to promote engagement in early occupations such as play, exploration and participating in personal care (activities of daily living). (Lekskulchai and Cole 2001 [A]; Hughes et al 2016 [A]; Duncan et al 2020 [B]) [New evidence 2022]	1A

33.	**It is recommended** that occupational therapists incorporate home routine/occupation-based approaches in early intervention programmes for children at risk for developmental delay as a means of promoting occupational performance. (Hwang et al 2013 [B])	1B
34.	**It is recommended** that occupational therapists be routinely referred preterm infants with the following co-morbidities: septicaemia, extremely low birthweight (ELBW), chronic lung disease, periventricular leukomalacia (PVL) or intraventricular haemorrhage (IVH) (grade III–IV), for early intervention. (Hintz et al 2008 [C])	1C
35.	**It is recommended** that occupational therapists working in early intervention settings with high-risk infants consider key elements when building a therapeutic collaboration with parents – promoting effective collaboration amongst multiagency providers, supporting family social/emotional needs in addition to infant developmental concerns, and consistency of service provision. (Ideishi et al 2010 [D])	1D

5.11.2 Recommendation 30: Promotion of cognitive performance

Spittle et al (2015) conducted an update to the Cochrane systematic review originally conducted by **Spittle et al (2007)** which aimed to compare the effectiveness of early intervention programmes (for preterm infants) over time. The review included 25 individual studies (19 randomised controlled trials, 5 quasi-experimental studies and 1 cluster analysis), which collectively included 3,615 children. The interventions included in the studies aimed to improve cognitive and/or motor outcomes and included a focus on the development of the parent–infant relationship and/or infant development. Most of the programmes included in the review commenced after the infants were discharged from the neonatal unit.

As expected, the studies contained a degree of variability in relation to the focus of the intervention being offered, the intensity of service provision, the characteristics of the infants and parents included and the length of follow up. The meta-analysis demonstrated that interventions improved outcomes in infancy and for preschool-aged children, though not for school-aged children. Motor outcomes were also noted to improve in 12 of the studies, indicating a positive response to early developmental interventions during infancy.

These findings were reflected in the systematic review conducted by **Orton et al (2009)** which also aimed to assess the efficacy of early intervention programmes in relation to cognitive and motor development. The review identified 18 studies that met the inclusion criteria, but only 11 papers were suitable for inclusion in the meta-analysis.

Studies that focused on cognitive outcome in infancy showed that the provision of early developmental intervention resulted in an increased developmental quotient on cognitive testing when compared with those infants who were receiving standard neonatal follow up. At preschool age, this improved outcome (as measured by average IQ) was maintained for infants receiving early intervention. By school age, no differences in cognitive outcome were noted.

Evidence overview

The evidence supporting the positive impact of the provision of early intervention to promote cognitive development through to preschool age in high-risk infants is strong. For those infants with identified developmental concerns, early intervention programmes that begin following the infant's discharge from hospital have been shown to benefit cognitive development/learning. The impact of these interventions in infancy and early childhood is a key finding supporting the proactive provision of early intervention services, rather than delaying until children present with difficulties at preschool or school age. The evidence for this recommendation is drawn from two high-quality systematic reviews (one of which has undergone updating/review).

No specific risks were reported in any of the studies for the infants receiving early developmental interventions.

5.11.3 Recommendation 31: Supporting parent experience of anxiety

Spencer-Smith et al (2012) conducted a randomised controlled trial which aimed to determine the longer-term effectiveness of the VIBeS Plus programme by reviewing caregivers and children at preschool age. VIBeS Plus is a home-based preventative care programme which aims to educate primary caregivers about evidence-based interventions for improving infant self-regulation, postural stability, co-ordination and strength, parent mental health and the parent–infant relationship. The programme is provided for infants born at <30 weeks' gestation as a series of nine home visits of 1.5–2 hours in length over the first 12 months of life following discharge from the neonatal unit. The study was conducted in Australia and included 120 children. The follow-up review was conducted when the children were 4 years' corrected age.

The findings of the study showed little difference in cognitive and motor outcomes for children receiving the VIBeS Plus intervention compared with those receiving standard follow-up services. However, key differences were noted for parents who had participated in the VIBeS Plus programme in relation to reporting fewer anxiety symptoms, and fewer were likely to be at risk for an anxiety disorder. This finding is particularly important given the high rates of parental distress after a preterm birth.

Evidence overview

There is strong evidence that the delivery of targeted early intervention offered in a preventative/health promotion model for high-risk infants can have positive impacts on parent mental health. In acknowledging the ongoing stress and anxiety that parents can experience following the birth of a high-risk infant who is either at increased risk for, or displaying, emerging developmental concerns, it is important that early intervention services are structured in a way that supports the promotion of parent mental health in addition to, and in support of, optimising infant development. The evidence for this recommendation is drawn from one high-level randomised controlled trial.

5.11.4 Recommendation 32: Promoting motor skills for participation in childhood occupations

Lekskulchai and Cole (2001) conducted a randomised controlled trial which aimed to examine the motor performance of infants born preterm following the provision of a programme designed to facilitate motor development. The study, conducted in Thailand, included 84 infants. The intervention was provided as a follow-up developmental physiotherapy programme; a set of developmental activities was provided to families each month from term-equivalent to 3 months' corrected age, with support for the parents in

learning how to provide appropriate facilitation for their infants. The motor-based interventions incorporated in the programme focused on functional movement skills, e.g. weight bearing in prone, development of supported sitting, bringing hands together in midline and to mouth, and the promotion of reach (for exploration of toys etc.).

The results from the study indicated that infants who were receiving the home-based intervention showed significantly greater improvement in the acquisition of their functional motor skills than infants in the comparison group. By 4 months' corrected age, infants who had received the intervention were demonstrating the performance of motor skills which were comparable with those infants in the comparison group who had been identified as at minimal risk for motor delay.

Hughes et al (2016) conducted a systematic review and meta-analysis to identify interventions that improve the motor development of preterm infants. Forty-two papers, which reported the results of 36 trials (including 25 RCTs and 11 non-RCTs), were included. Collectively, the original studies reported on motor outcomes in 3,484 infants. With some variability, the study interventions commenced between when the infant was in the neonatal unit and up to 6 months of age. Duration and frequency of intervention provision in the studies were variable. Meta-analysis of the data was conducted at different age-points. The results indicated that interventions can enhance the motor development of preterm infants, though this effect is variable over time. Significant differences were found at 3, 6, 12 and 24 months' corrected age, although the effect size diminished over time.

Duncan et al (2020) conducted a prospective cohort study to determine associations between hand function at age 18–22 months and motor performance at 6–7 years of age in 313 extremely preterm children (EPT). Hand function was assessed at 18–22 months in a dichotomous deficit vs non-deficit classification in relation to pincer and grasp capacity, hand preference and performance of bimanual functions. School-age motor performance was assessed using the Movement Assessment Battery for Children (MABC). The results indicated that EPT children with early hand function deficits were more likely to have definite school-age deficits on all of the MABC subtests. When children had diagnosed cerebral palsy or cognitive disability (IQ <70), hand function deficits remained significantly associated with manual dexterity performance difficulties at school age.

Evidence overview

There is good evidence that the provision of early intervention programmes for high-risk infants in the first months following discharge from the neonatal unit can promote positive outcomes in the acquisition of functional motor skills. Further support for the need for early intervention is suggested by evidence indicating a relationship between fine motor function before 2 years of age and school-age fine motor performance.

The evidence for this recommendation is drawn from one high-quality systematic review and meta-analysis, one randomised controlled trial and one cohort study.

The development of functional motor skills is a key component of occupational therapy practice, as motor and postural control provides a base for the ongoing development of refined motor control required to promote successful engagement in play, and early activities of daily living.

5.11.5 Recommendation 33: Incorporating occupation-based routines into practice

Hwang et al (2013) carried out a randomised controlled trial that aimed to compare traditional home visiting with a routines-based early intervention (RBEI) model with children at risk of, or with, developmental delay. The study was conducted in Taiwan and included 38 children up to 3 years of age. RBEI is an approach that focuses on the provision of a coaching model for parents to support their child's participation in self-care and family routines, rather than traditional developmental domains.

When measured by the performance of relevant ADL skills (by the Paediatric Evaluation of Disability Inventory), children and families who were receiving the RBEI model demonstrated faster progress in developing independence in self-care and social functions, at both the conclusion of three months of intervention and at six-month follow up. Evaluation of the use of collaborative goal setting between parents and providers also demonstrated faster attainment of family goals for the children and families receiving RBEI than those receiving standard care. While both RBEI and traditional home-visiting early intervention models supported the children's developmental progress, the RBEI was more effective in promoting functional outcomes and reaching family-centred goals.

Evidence overview

There is moderate-quality evidence that the provision of an early intervention model that focuses on the child's participation in family routines and activities shows improved attainment of functional skills for children at risk of, or with, developmental delay when compared with a traditional early intervention home-visiting model. While both RBEI and traditional home-visiting early intervention models supported the children's developmental progress, the RBEI was more effective in promoting functional outcomes and reaching family-centred goals.

The focus of integrating intervention approaches into everyday tasks and routines is a key theory underpinning occupational therapy practice across all domains and provides good evidence of the benefits of incorporating a family-centred, occupation-based approach when working with young children and their families.

5.11.6 Recommendation 34: Identification of at-risk infants for early intervention

Hintz et al (2008) conducted a retrospective analysis of a cohort of extremely preterm infants in the United States, who were routinely followed up as part of the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network. The review was conducted when the children were 18–22 months' corrected age and aimed to determine the special outpatient service (SOS) use, need, associated factors, and the neurodevelopmental and functional outcomes for infants born extremely preterm. The analysis included data from 2,315 children and families. Specialist outpatient services referred to a community nurse, occupational therapy, physiotherapy, speech and language therapy, early intervention, social work, medical specialist support, and neurodevelopmental and behavioural services.

The study indicated that 54.7% of extremely preterm infants had or were using three or more specialist outpatient services by 18–22 months, with 19% accessing more than six specialist services. The most common risk factors associated with increased use of SOS were sepsis, birthweight, postnatal corticosteroid use, chronic lung disease, periventricular leukomalacia (PVL) or intraventricular haemorrhage (IVH) (grade III or IV). Male infants were also identified as more commonly requiring support from SOS.

Stark et al (2020) conducted a descriptive research audit of the long-term developmental outcomes of infants with hypoxic ischaemic encephalopathy (HIE) who received therapeutic hypothermia (TH). Thirty infants who had received TH were enrolled. Given the resource-restricted location of the study, two locally-developed tools were used to assess developmental outcomes. These were the Strive Towards Achieving Results Together (START) to assess developmental outcomes from birth to 3 years, and the Early Childhood Developmental Criteria (ECDC) to assess cognitive, fine motor and gross motor development outcomes at 4 and 5 years of age. Children with cerebral palsy were assessed with the Gross Motor Function Classification System. Two children were lost to follow up. Of the remaining 28 children, 20 presented with typical development and eight with cerebral palsy. A significant association was identified between severity of HIE diagnosis and cerebral palsy.

Evidence overview

The evidence for the identification of high-risk infants who ultimately require provision of specialist outpatient services is low. However, one study involved a large, comprehensive cohort of extremely preterm infants and indicates that the prevalence of the need for access to specialist outpatient services for this group of infants is high. The other study was of very low quality but also indicated an association between a high-risk diagnosis (HIE) and later motor outcomes.

Infants who are considered high risk as a result of prematurity or other health factors may experience ongoing developmental concerns that can impact their participation in infant and child occupations. It is therefore recommended that infants born with specific medical issues such as sepsis, ELBW, BPD chronic lung disease, PVL or IVH (grade III–IV) are routinely referred for specialist outpatient services, including occupational therapy.

5.11.7 Recommendation 35: Parent–therapist partnerships

Ideishi et al's (2010) qualitative study aimed to explore the perspectives of parents and therapists of the role of a therapist in co-ordinating care between early intervention and medical services. This study was conducted in the United States and included 50 participants (16 parents and 34 healthcare providers).

This study provided some illumination as to how these collaborations are orchestrated between parents and providers. Parents identified that therapists often assisted by interpreting medical information into useful and understandable terms for them. They also acknowledged that, as parents, they often needed to provide a bridge between providers involved in their child's care who seemed to have little time to communicate with other providers. The different approaches used by different providers often caused confusion for parents, as did situations when conflicting views and recommendations were offered by people involved in their child's care. Therapists in community-based services emphasised the need to provide support for a family's social and emotional needs, more so than hospital-based therapists. Therapists also identified that they often lack knowledge about the role/scope of other providers that might be involved in the care of a child.

Gmmash and Effgen (2019) conducted a national survey (n=269) in the United States to explore the practices in use by physiotherapists and occupational therapists in early intervention (EI) for infants with or at risk of cerebral palsy. The majority of respondents commenced EI services before 6 months of age. Only 4% of therapists used the General Movements Assessment for early detection of cerebral palsy. A variety of other outcome

measures were used to assess the overall development and severity of motor delays in the infants. Most respondents provided directed interventions for skill attainment (e.g. head control). Most providers (89%) considered parent/caregiver goals to be the most important factor in the customisation of an EI plan, though 74% rarely or never used tools to assess parent satisfaction or to assist with goal prioritisation. Seventy-five per cent of therapists provided parents of infants at risk of CP with a home programme. Environmental enrichment and parent coaching were reported by 39% and 27% respectively. The authors concluded that therapists were not consistently using the recommended practices for early detection of CP, parental involvement, goal identification, home programme planning and environmental enrichment, to advance the motor development of infants with or at risk for CP and maximise parental engagement in the infants' therapy as much as has been suggested by the evidence base.

Evidence overview

The quality of the evidence for the impact of collaborative parent–therapist partnerships is low. One study identifies the likelihood that high-risk infants with emerging developmental concerns may be referred to a range of early intervention providers, with potential for inconsistency between service models and approaches. This leaves parents needing to navigate and advocate for services that comprehensively support their child's and family's ongoing developmental needs. The second study, based on a current practice survey, reports that therapists may not be consistently using best practice strategies to support and maximise parent engagement. Therefore, it is recommended that therapists working in early intervention services should use best practice evidence to support parent participation and support their engagement in EI services and acknowledge the role that parents play in managing their contacts with multiple service providers, ensuring clear communication across agencies, and supporting the child and family as a whole.

5.12 Potential impact of the recommendations

The potential impact of the recommendations has been considered across a range of domains.

5.12.1 Desired outcomes

The development and review of this guideline has produced a robust evidence-based resource that provides recommendations for occupational therapy assessment and intervention with the aim of improving services for high-risk infants and their families. These recommendations may contribute to the following outcomes:

- Each high-risk infant and their family have the opportunity to be referred to/receive specialist occupational therapy services within each neonatal network.
- High-risk infants and their families who receive specialist occupational therapy services perceive benefit from occupational therapy input.
- High-risk infants (and their parents) experience individualised, adequate and consistent pain management throughout the neonatal admission.
- High-risk infants (and their parents) experience an individualised, family-centred approach to supporting sensitive and contingent engagement in co-occupations that enhance the development of the parent–infant relationship.

- High-risk infants (and their families) benefit from smoother transitions between hospital and community neonatal services, which ensure continuity of support for families and enable more effective service delivery.

The recommendations contained within the guideline provide sound evidence and a base from which occupational therapy and neonatal services can work collaboratively with commissioners to support the commissioning of neonatal services that include occupational therapy as part of multidisciplinary teams within neonatal networks, with the aim of ensuring that high-risk infants and their families have access to comprehensive multidisciplinary team services which support consistent provision of developmentally supportive care for infants, and sensitive parent support.

The potential value added by the integration of occupational therapy services into a neonatal multidisciplinary team and neonatal network is easily articulated, resulting in improved understanding of, and support for, the contributions of occupational therapy services to neonatal care.

The recommendations contained within the guideline support occupational therapists working with (or aspiring to work with) high-risk infants and their families to identify and pursue appropriate knowledge and training to ensure safe and effective service delivery.

They support the development of increased availability and comprehensive occupational therapy services for high-risk infants in the first two years of life to maximise developmental gains, participation in childhood occupations and the provision of guidance for parents.

Increased access to occupational therapy services may result in cost savings across both the health and education sectors as a direct result of decreased hospital admission for infants, reduced need for ongoing medical appointments, decreased incidence of developmental/educational concerns due to earlier identification and support, and decreased incidence of mental health concerns for both parents and high-risk infants through early childhood.

The identified recommendations support the articulation of the scope of a specialist occupational therapy service, which enables projections to be made for service needs.

The guideline is used to support the development of subsequent tools and resources that will further enhance the provision of occupational therapy, such as the development of complementary competency standards, education initiatives to support occupational therapy training etc.

5.12.2 Risk management

Sensitive and appropriate assessment

The evidence review did not indicate specific assessment tools to include in the recommendation. It is appreciated that there is a range of specific and sensitive assessments for the neonatal population which occupational therapists may utilise. However, in all instances, the choice of assessment should consider each specific infant's vulnerabilities, including gestational age and medical co-morbidities, to ensure that at no time is the infant placed under additional stress. For fragile infants, detailed, structured neurobehavioural observations provide rich information on the infant's strengths and vulnerabilities, and support the identification of parent and caregiver strategies to include in a developmentally supportive care approach. The selection of specific assessment tools will be both informed by an individual practitioner's clinical judgement and influenced by practical elements such as availability and training/certification competencies. Many neonatal neurobehavioural

assessments require specialist training and certification, and occupational therapists working in neonatal units must not utilise these assessment tools unless they have been appropriately trained.

Sensitive handling

Equally, high-risk infants may present with a range of vulnerabilities in which their health status can be significantly compromised via inappropriate and insensitive handling. When working with these infants, occupational therapists must have developed competence in handling skills appropriate to this population. All infant handling should be constantly monitored, based on the infant's neurobehavioural cues, to ensure that the pacing and timing of interventions remain supportive at all times.

Knowledge and skills across all occupational performance domains

The knowledge and skills required to practise in the neonatal unit are not core elements of standard occupational therapy training pathways. Therefore, occupational therapists providing services into neonatal units must undertake specialist knowledge and skill development to support their practice, and manage potential risk to vulnerable infants and parents. Specialist training pathways may include continuing education and mentoring. The AOTA position paper (Vergara et al 2006) on the knowledge and skills required by occupational therapists working in this setting provides a robust outline of the attributes required by occupational therapists working in the neonatal unit. Equally, the recommendations outlined in this document and the forthcoming RCOT neonatal occupational therapy career development framework (in development) may be used for individual therapists to consider their own knowledge and skills in the provision of safe and effective interventions incorporating developmental care, postural support, pain management, feeding, psychosocial support of parents and early intervention. Occupational therapists working in neonatal settings should not provide intervention elements in which they have not developed appropriate competencies. This may include the requirement for specialist training and/or certification in specific intervention approaches described in the evidence summaries.

Occupational therapy expertise

On the basis of the specialist knowledge and practice skills required by occupational therapists working in the neonatal setting, we would suggest that these roles are commensurate with experienced/senior therapists. In line with the BAPM (2010) recommendations, occupational therapy positions in neonatal services should be banded at a minimum Band 7 level. It is recognised that some neonatal units currently employ therapists at Band 6 level – it is recommended that therapists working at this foundation level have access to a more experienced neonatal OT in the unit/trust for training, education and clinical supervision to ensure safe and effective practice. Indeed, due to the complexity of infant presentation in many instances/units, it may be appropriate for these roles to be considered at a clinical specialist level (Band 7/8). All occupational therapists who are new to working in neonatal settings must have access to supervision and/or mentoring. The establishment of occupational therapy network roles may provide some scope for the provision of supervision and mentoring models for occupational therapists employed in specific geographical areas. We also recommend that therapists beginning practice in the neonatal setting have existing robust experience in children's occupational therapy services, with refined occupation-based assessment and intervention skills with infants, and recognise the importance of working within a family-centred care approach. This would form a practical basis from which to extend knowledge and skills development into the specialist area of the neonatal unit.

Education and training availability

It is acknowledged that developing specialist skills and knowledge in neonatal occupational therapy can be difficult in the UK due to the current paucity of defined and funded roles in neonatal units and limited access to experienced occupational therapists for shadowing and mentoring opportunities. However, recent developments in neonatal occupational therapy and developmentally supportive care approaches have made basic and intermediate-level training far more accessible. Knowledge and skill development can be accessed through a variety of education modes, including face-to-face, online modules and lectures, and clinical supervision. Occupational therapists considering developing practice skills in the neonatal setting should avail themselves of these opportunities. Additionally, specialist certifications in areas of neonatal assessment and practice are available from a range of national and international providers; these certifications may be pursued by individual therapists to continue to refine and enhance their therapy service provision. There remain some limitations to education and training availability at the competent to expert practitioner level, with some specialist programmes being unavailable in the UK.

Collaborative team working

While this document provides recommendations for occupational therapy practice, it is recognised that some areas of practice outlined will overlap with a range of other professionals working in the neonatal setting. In all instances, occupational therapists should work collaboratively within the multidisciplinary team to ensure the delivery of a comprehensive and consistent approach to service delivery for infants and their parents throughout admission and with other agencies following discharge.

Financial risk

It is recognised that some neonatal units will not currently have access to, or funding for, occupational therapy services. The provision of occupational therapy services within the scope outlined in this document may not be achievable with current financial resources. The cost–benefit of enhancing neonatal services to incorporate occupational therapy provision as part of the multidisciplinary team is a decision for local trusts and networks. Neonatal networks and/or units wishing to establish or enhance current levels of occupational therapy service provision may find the guideline document and recommendations of use when working with specialist commissioners and building business cases for service development.

Additionally, employing occupational therapists who are without prior experience in neonatology to work in neonatal units will require financial investment in skills and knowledge training to ensure relevant practice competencies.

5.12.3 Generalisability

Due to the broad scope of the guideline objective, the studies included in the evidence review were heterogeneous, with variations in sample populations, in the type, amount and frequency of specific interventions, and in the availability of occupational therapy services within the service model.

Geographical variations in the core domains of occupational therapy practice in neonatal settings have been taken into account in the development of the recommendations, to ensure that findings are pertinent to the UK context. Additionally, variation in intervention approaches and evidence outcomes have been reviewed in detail when judging the generalisability to the UK population. Despite the core evidence being drawn from diverse contexts, all of the infants within the individual studies were comparable with the guideline scope.

5.12.4 Social determinants of health

The reality of having a high-risk infant and the potential requirement for ongoing access to early intervention services can be influenced by a range of existing and emerging issues for families. Issues to be considered within the implementation of the guideline include:

- The increasing awareness of the relevance of epigenetics and the impact of the infant's early experiences on long-term disease processes, as a driver for the importance of ensuring that all high-risk infants receive individualised, family-centred, developmentally supportive care.
- Supporting parents in understanding the crucial importance of their relationship with their infant's wellbeing and development in both the short and long term (UNICEF United Kingdom 2022), to underpin approaches that enable parent engagement.
- Reducing the late presentation of children with occupational performance concerns at school age.
- Ensuring service provision is both family centred and culturally sensitive to support parent engagement of all families of high-risk infants.
- Supporting positive parent engagement in service provision as a means of building empowerment – leading to increased confidence in the longer term in relation to advocating for services/support for their growing children.
- Supporting positive parent–infant engagement and occupational participation for parents who may be experiencing mental/emotional distress, stress, depression or anxiety as a result of the birth of their preterm infant/s.
- Providing appropriate support for families who may have experienced prenatal mental health conditions.
- Recognising the financial burden of having an infant who requires intensive care services.
- Supporting the recognition of geographical inequalities in relation to the type/frequency of occupational therapy services available in neonatal units and affiliated services.

6 Parent perspectives

The target audience of the full guideline document is primarily occupational therapists working in neonatal and affiliated services, including paediatric settings. While of potential interest to parents, the Guideline Development Group acknowledged that it was not written specifically for a lay audience.

Parent perspectives are integral to the guideline development process and involvement took place through consultation on the draft scope and draft guideline (see Sections 9.3 and 11.4).

6.1 Parent consultation – first edition

In the first edition, parents were also engaged in the drafting of the guideline recommendations. Parent engagement was sought in two ways:

- Through an invitation disseminated on the Bliss Facebook page advising parents of the guideline project and seeking their feedback on the draft recommendations.
- Through direct invitation to current and previous parents affiliated with neonatal services represented by the guideline group membership.

Mechanisms for providing input into the development of the draft recommendations were also enabled in two ways:

- Two parent engagement events were conducted in November 2016, where the draft recommendations were discussed with parents. Discussion about the recommendations was facilitated by a guideline group member. Key comments from parents were minuted. Parent input was also sought in shaping the wording of the recommendations. Summary written comments from the parents were collected using a pro forma template. These events were held in Leeds and London, with one parent contributing in Leeds and five in London.
- A direct phone/email link was provided to one of the members of the guideline group for interested parents to contact and provide feedback on the draft recommendations. Ultimately no parents provided feedback in this way.

Parent feedback was specifically sought in the following areas:

Q1: Do you think the recommendations are easy to understand? Are there any changes you would suggest?
Most parent respondents reported that the recommendations were fairly easy to understand, but recognised that some of the terminology was more complex and may require more detailed explanation. Some parents also reported that the use of occupation-centric language was unfamiliar to them, and so suggested simplifying some of the recommendations accordingly. These recommendations were reviewed, and amendments made accordingly.

Q2: Do you think the recommendations reflect your experiences of being involved with neonatal occupational therapy services?
There was variability in the response of parents which closely reflected the degree to which they had been involved with occupational therapy services while their infant was admitted to a neonatal unit. Three parents who had received ongoing support by occupational therapists during their neonatal unit admission concurred that the recommendations were reflective of their experiences of occupational therapy. Another response recognised that there is some overlap in the recommendations with services provided by other members of the multidisciplinary team, and that, in their situation, some domains were supported by other professionals. Finally, one parent shared that while the recommendations did not reflect her and her infant's specific experience, they served to outline what is best practice.

> "Not all are relevant … feeding was discussed by the midwife on the ward"
>
> "Unfortunately not – but best practice is what each unit should aspire for"

Q3: Do you think the practice recommendations would be of benefit to you and your child (now or in the past), even if this level of service wasn't available to you at the time?
Parents generally reported that the recommendations would be/were of benefit, though recognised that in each of their individual situations, some would be more relevant than others. One parent identified the scope of the guideline ending at 2 years of age, commenting that understanding what happened beyond this point in terms of service transition would be advantageous.

> "Absolutely!"
>
> "Yes, a lot of the recommendations would have been helpful"

Q4: Are there any areas of practice that you feel are missing from the recommendations?
Based on their experiences, there were no areas of practice identified by parents that were not covered in the recommendations. One parent did share the value in occupational therapists providing information/support in both verbal and written forms, due to the high information processing demands parents are faced with when their infant is receiving care in a neonatal unit.

> "The availability of written information/guidance to support (verbal) information … when dealing with a difficult time on the ward, it is sometimes difficult to take in any information"

Q5: In your experience, what do you think is the most important support that neonatal occupational therapists could/did provide to you and your baby?
Parents provided a variety of responses about what they considered to be the most important support provided by an occupational therapist. This highlights the individuality of all families with whom occupational therapists work, and the importance of practising within

a family-centred care model, that is, one that works with families to identify their specific strengths and support needs. Parents identified important areas of support as education on developmental milestones specific to preterm infants, learning to read infant cues, to increase parent confidence, and support with positioning, feeding and motor development. Access to occupational therapy services during a neonatal unit admission was also highlighted by one parent.

> "Reassurance – some support that our daughter was progressing well. It was positive that the OTs look at the 'person' not a scan; as a parent this is what you want to hear"
>
> "Helping us to feel confident about babies' needs and developmental care"
>
> "Just having easy access to an OT"

The parent feedback was then considered collectively in refining the final recommendations. The responses provided invaluable insights and comments and led to amendments, and the inclusion of specific quotes, within the first edition of the guideline.

6.2 Parent consultation – second edition

In the second edition of the guideline, parents' opinions were sought via an online survey. The Guideline Review Group developed an online questionnaire that was approved through the RCOT governance process. The survey was facilitated by JISC Online Surveys, a GDPR-compliant online survey platform, that was open from 22 November 2021 to 4 January 2022. The survey focused on recommendation categories that included new recommendations: pain management, infant massage and positive touch, and parental support. A copy of the questionnaire can be found in Appendix 10.

The survey was disseminated by stakeholder organisations through their networks, and by the Guideline Review Group members' networks where appropriate.

6.2.1 Respondent profile

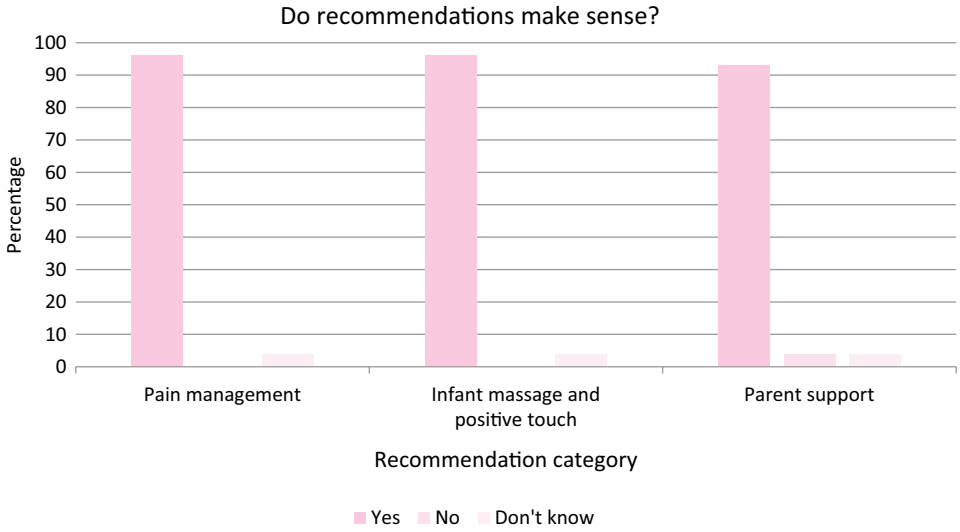
Twenty-seven parents responded to the survey. Twenty-five respondents described themselves as 'White (English/Welsh/Scottish/Northern Irish/British/Irish/Gypsy or Irish Traveller/Any other White background)', one described themselves as 'Asian/Asian British (Indian/Pakistani/Bangladeshi/Chinese/Any other Asian background)' and one parent preferred not to say. The Guideline Review Group acknowledged the lack of ethnic diversity in the parental response.

Nine parents (33%) said they had occupational therapy input while their infant was in the neonatal unit. Seventeen (63%) did not and one was unsure. Of those who did have occupational therapy input, just over three-quarters (78%, or seven parents) felt they understood the role of the occupational therapist.

6.2.2 Results

Overwhelmingly, parents felt the recommendations made sense, with more than nine out of ten parents saying they made sense in each recommendation category.

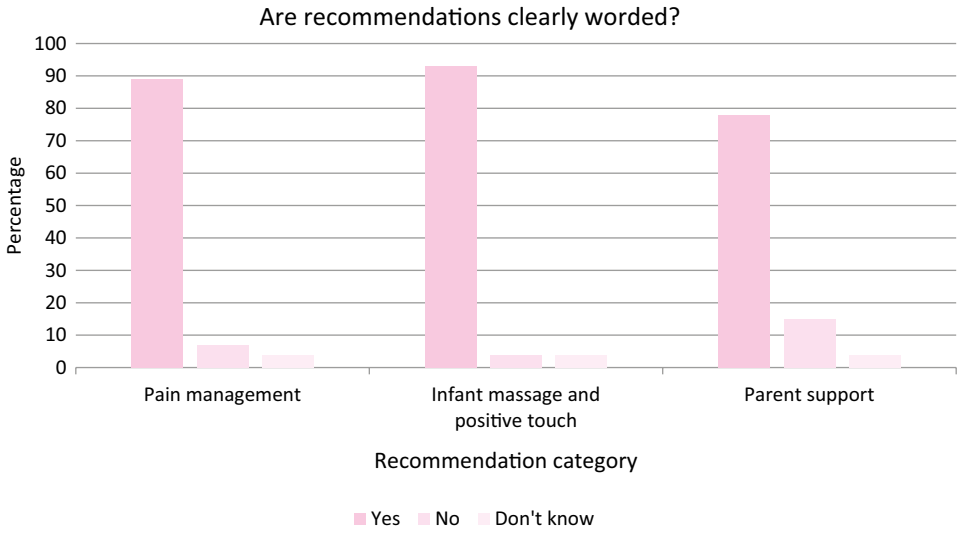
Chart 6.1



*Percentages may not sum to 100 because of rounding.

While still positive, parents were less sure that the recommendations were clearly worded. Parents questioned the parent support recommendations most, with five parents (15%) saying they were not clearly worded.

Chart 6.2



*Percentages may not sum to 100 because of rounding.

When asked why they did not think the recommendations were clearly worded, parents questioned the terminology or phrasing of the recommendations. They suggested the recommendations contained 'jargon' or were too clinically worded and were lengthy.

"Some parents will not understand the terminology used" (referring to the pain management recommendations)

"Too wordy and too clinical" (referring to the parent support recommendations)

"Number 2 is too lengthy and it takes a while to decipher the point" (referring to recommendation 23 in the parent support recommendations)

"I do understand the vocabulary used, however recommendation 2 in particular is very jargon heavy and could be off putting for many people" (referring to recommendation 23 in the parent support recommendations)

When asked if they had any further comments to make about the recommendations, some who had agreed the recommendations made sense and were clearly worded suggested improvements.

"While I understand the term 'self efficacy', it isn't commonly used day to day and might be better to use a more straightforward term" (referring to the pain management recommendations)

"'Parenting occupations' is very clinical sounding" (referring to parent support recommendations)

Some parents voluntarily voiced their support for infant massage and positive touch, noting how positive an experience this was for them. Indeed, aside from ideas to improve the recommendations, parents most commonly mentioned infant massage and positive touch when asked for their thoughts on the recommendations.

"I personally found that if my son had a really hard day or I was really anxious, I would do maybe 5 minutes of massage or just touch and it seemed to help ease my anxieties and relax my son"

"Should be encouraged during the NICU/SCBU phases when parents are most afraid of their fragile babies" (referring to the infant massage and positive touch recommendations specifically)

"Just that they should be actively encouraged and parents supported to be able to do them" (referring to the infant massage and positive touch recommendations specifically)

The GRG valued the opinions of parents who responded to the survey and considered where they could amend the wording of recommendations to clarify.

7 Implementation of the guideline

This practice guideline aims to provide occupational therapists with specific recommendations to support the use of an occupation-focused approach in neonatal and early intervention settings.

Familiarity with the guideline document will be an important first step for both individual practitioners and their managers. It is, therefore, imperative that occupational therapists and managers working in this clinical area take responsibility for reviewing the guideline recommendations within the context of their practice.

Bringing the guideline to the attention of colleagues within the multidisciplinary team and service commissioners should also be a priority.

A further action to facilitate implementation must be for lead therapists to consider the 'levers' and 'barriers' within their local organisation and culture that may have an impact on any changes that may be necessary to practice. Section 7.2 identifies some potential barriers that may be applicable, while Section 7.3 provides details of resources to facilitate implementation.

7.1 Dissemination and promotion

Awareness and implementation of this practice guideline are important if it is to influence and have an impact on occupational therapy practice.

Following publication, the full practice guideline has been made available to download freely from the Royal College of Occupational Therapists' website.

The guideline has been promoted to its key target audience of occupational therapists and to relevant others using professional networks and publications, the internet and social media channels.

7.2 Organisational and financial barriers

The recommendations stated within this guideline document are intended to help occupational therapists to deliver occupation-focused practice. It is recognised, however, that there will be potential barriers, both organisational and financial, which may influence application of the recommendations. It is important that occupational therapists take these into account when implementing this guideline. The most likely barriers, described below, were identified via consensus agreement of the clinical experts in the Guideline Development Group.

The availability of occupational therapy services in neonatal units across the UK is inconsistent. While this guideline will help build awareness of the potential contribution of occupational therapy to the neonatal multidisciplinary team, it is recognised that this will be accompanied by some workforce and funding pressures. First, while there may be a recognised need for occupational therapists, limited resources may mean the funds are not available to create new posts in units that do not currently employ occupational therapists. In these circumstances, it is suggested that neonatal units liaise with their local acute or community paediatric occupational therapy service to consider service development

opportunities. This may involve the development of a joint business case to present to specialist commissioners for funding to either establish new or enhance existing funding for occupational therapy services for high-risk infants and their families in the neonatal unit and follow-up services. As neonatology is an area of specialised practice, this guideline highlights the need for appointing senior-level therapists in this setting. This is an additional cost factor that needs to be considered in planning funding for service development.

Second, it is also recognised that there is currently a small pool of occupational therapists with experience of working within neonatal services across the UK. Therefore, workforce development plans will need to consider how to ensure appropriate skills and knowledge for occupational therapists. There are a number of elements to be considered:

- Occupational therapists newly appointed to neonatal services should have significant existing experience in the paediatric setting.

- A specific mentoring/supervision plan (alongside a specialist training plan) should be implemented to facilitate occupational therapists' specific development regarding NICU services. This could be conducted as a hybrid model with a local neonatal practitioner (e.g. practice development nurse, allied health professional), with an external occupational therapist mentoring arrangement. The practicalities and costs of supporting these arrangements would need to be considered. The career development framework for occupational therapists working in neonatal care, which is currently being developed, would form an ideal adjunct for therapists commencing work in this area to help shape the training and supervision approach.

- Access to specialist training will need to be enabled. While a range of early to mid-career training regarding neonatal skills and knowledge is available in the UK for occupational therapists to access, there are costs involved in participating in these training programmes. Other mechanisms by which to access specialist training from an international platform (e.g. online webinar training from high-quality providers) can prove a pragmatic and more affordable means of ensuring access to specialist learning. At the highly experienced/specialist end of the career spectrum it should be recognised that some training programmes are of very high cost, and some are only available internationally.

- The use of some specific assessment and clinical tools requires specialist training and certification before they can be used by occupational therapists in neonatal services (e.g. Neonatal Behavioural Assessment Scale, General Movements Assessment, Assessment of Preterm Infant Behaviour, Bayley Scales of Infant Development etc.), and will therefore have financial costs and implications before being introduced into practice.

In the consultation process, awareness was raised about the potential difficulties that may arise from an individual therapist's or an organisation's ability to implement the recommendations in a particular setting. The Guideline Development Group recognises that the recommendations included in these guidelines will not necessarily be possible to implement in a standard way across every setting. This is primarily due to access to, and funding for, occupational therapy services. When implementing these recommendations, occupational therapists will need to consider their resources and prioritise where necessary. It should be noted that the recommendations in the guideline overlap with key service delivery areas of a range of other professionals in the neonatal unit. Therefore, it is anticipated that the implementation of the recommendations will be planned and delivered

in a local, specific context, based on service need, funding resources and the overall contributions of the neonatal multidisciplinary team.

Occupational therapy in neonatal services will require ongoing linking via networks of practitioners. Occupational therapists should ensure involvement in the activities of their local neonatal network to continue to build awareness of the occupational therapy contribution to neonatal care delivery. To prevent isolation, ensure currency of knowledge and awareness of ongoing developments, occupational therapists should also ensure they access a relevant professional forum. Within the UK, the Neonatal Occupational Therapy Forum (as part of the RCOT Children, Young People and Families Specialist Section) provides a collegiate link with other therapists and is a place to share resources and ideas. Additionally, other professional networks (such as those run by Bliss, or the National Association of Neonatal Therapists) may also be useful in ensuring access to support and information.

7.3 Implementation resources

Three core implementation resources are available to support this practice guideline.

7.3.1 Quick reference and implementation guide

The quick reference and implementation guide is intended to be used by practitioners as an easily accessible reminder of the recommendations for intervention. It should ideally be used once the practitioner has read the full guideline document, to ensure an appreciation of the context and development of the recommendations.

The quick reference guide includes the following:

- Introduction.
- Policy and service delivery context.
- The occupational therapy role.
- List of the recommendations, their strength, and the quality of the evidence leading to their development.
- Evidence overview.
- Tips for implementing the recommendations.

7.3.2 Audit form

It is recommended that occupational therapists use the Royal College of Occupational Therapists' audit tool that supports this guideline.

The audit form for this guideline provides a template for individual occupational therapists or services to audit and review their current interventions against the recommendations. The aim is to encourage reflection on current practice and to consider, where this does not follow the recommendations, the clinical reasoning in place to support decisions.

A baseline assessment conducted using the audit tool can be repeated to enable review of progress on actions identified from the audit. It can be useful to undertake a routine audit

every one or two years to monitor ongoing compliance. The audit form, while initially providing a tool for use within an individual/service context, offers the potential for future benchmarking and wider comparative analysis.

Recommendations, for which there is a transdisciplinary component, may be usefully audited jointly with other members of the multidisciplinary team. Likewise, the occupational therapist may be involved in audits related to other frameworks, such as the Bliss Baby Charter Standards and audit tool (Bliss 2020).

7.3.3 Continuing professional development/knowledge transfer resource

The continuing professional development resource is interactive and can be tailored for local use. The session can be used for group or self-directed learning, or for raising awareness of the guideline at multidisciplinary meetings, study days or events.

A feedback form is also available to provide comment on the guideline and implementation resources to the Royal College of Occupational Therapists.

7.3.4 Other associated resources

Additional resources available include:

- Occupational therapy staffing on neonatal units (RCOT 2018).

Accessing the implementation resources

The quick reference and implementation guide, audit form and continuing professional development session resources are available as separate documents.

These can be downloaded, together with the full guideline document and evidence tables, from the practice resources section (Practice guidelines) of the Royal College of Occupational Therapists' website: https://www.rcot.co.uk/practice-resources/rcot-practice-guidelines

7.3.5 Implementation in practice and future developments

The development of this guideline serves to bring together the large body of evidence that contributes to occupational therapy practice with high-risk infants in the neonatal unit and early intervention settings. It is beyond the scope of this guideline to specify models for occupational therapy services or provide discrete recommendations for specific assessment tools and intervention strategies.

To support the consideration of how neonatal occupational therapy services can be delivered, some examples have been provided within Appendix 4. Two key elements are provided:

- A framework for the identification and prioritisation of infants to be referred to occupational therapy services based on biomedical and psychological factors. This tool has been adapted to reflect the content of the guideline recommendations and provides a process by which services can be prioritised, with suggested occupational therapy approaches.

- Five examples of occupational therapy services in neonatal settings, including details on staffing, referral criteria, funding, and assessment and intervention approaches utilised in practice. These examples aim to give a sense of the variety with which occupational therapy services may be implemented within neonatal networks.

It was recognised by the Guideline Development Group that this revised guideline comes at a time when a range of other developments that will add increasing specificity to the provision of occupational therapy services in neonatal settings in the UK is occurring. Resources that are currently in development include:

- career development framework for neonatal occupational therapy practice
- education modules and pathways developed for foundation, enhanced and advanced neonatal occupational therapy practice (in collaboration with Health Education England).

Other potential resources that have been proposed for development include:

- a summarised version of the guideline that is written with and for parents of high-risk infants
- exemplar job descriptions for occupational therapy positions in neonatal services
- exemplar business case templates for the establishment of occupational therapy positions in neonatal services
- recommendations for additional continuing education requirements within the field, incorporating a range of training modes (e.g. continuing education programmes, mentoring etc.).

The Royal College of Occupational Therapists Specialist Section – Children, Young People and Families Specialist Section (Neonatal Forum) will be responsible for the implementation of ongoing work streams to develop future resources.

8 Recommendations for future research

The review of the evidence within the guideline scope identified a small body of occupational therapy primary research and a larger body of occupational therapy relevant research, confirming a need for further research that explores and evaluates the added value of neonatal occupational therapy services for high-risk infants and their families.

Future research topics identified from the evidence and from the expertise of the Guideline Development Group include:

- **Economic evaluation**. Economic evaluations and health economic data are needed to establish the cost-effectiveness of neonatal occupational therapy early intervention, provided for high-risk infants and their families, in reducing later expenditure on health, education and social care support services. This includes the impact that an improved continuity of care from occupational therapy services from within the neonatal unit to home has, and the subsequent impact on service utilisation and avoidance of service attrition (Weatherly and Davis 2021, World Federation of Occupational Therapists 2021).

  More specifically, implementation of cost–benefit, cost-minimisation and cost-utility evaluations of improving neonatal outcome and reducing neonatal morbidities are needed, including:

  - access to antenatal care
  - perinatal interventions to delay preterm delivery wherever feasible
  - improving parental health status and practising cost saving and effective neonatal intensive care treatment.

- **Outcomes and effectiveness**. Studies to determine the effectiveness of the implementation of neonatal occupational therapy as a component of a complex intervention supporting high-risk infants and their families, taking into account factors such as:

  - The association between referral for neonatal occupational therapy early intervention and child outcomes at preschool, school age and beyond.
  - Identification of the most effective tools and/or approach for occupation-based assessment with high-risk infants and families.
  - Identification and/or development of occupational therapy specific outcome measures that capture infant and parent occupation-based intervention outcomes in the neonatal unit setting.
  - The outcomes for interventions that specifically guide and support parents in sensitive and contingent occupational engagement with their high-risk infants, in terms of infant development, parent self-efficacy and parent/carer wellbeing.
  - Evaluation of the sensitivity of neonatal caregivers in individualised infant care following education and training delivered by occupational therapists.

- **Parent perspectives**. Studies that explore parent's experiences, including:
  - Perceived health/developmental benefits of neonatal occupational therapy for high-risk infants of parents and neonatal staff.
  - Parents' perceptions of the psychological impact of participating in an occupation-centred occupational therapy service during their infant's admission to a neonatal unit.
  - Parents' perceptions of the attainment of parenting occupations in relation to participation in caregiving occupations, and empowering parents to facilitate inclusion in family-centred care (e.g. participation in developmental care rounds).

9 Guideline development process – first edition

Sections 9 and 10 provide the details of the development process and methodology for the first edition of the guideline which followed the *Practice guideline development manual*, third edition (COT 2017). Section 11 outlines the review process and update for this second edition. Detailed information on the steps in the guideline development process can be found in the *Practice guideline development manual*, fourth edition (RCOT 2020).

9.1 Guideline Development Group

The membership of the core Guideline Development Group comprised 11 occupational therapists with expertise in the neonatal field, a representative from Bliss and a representative from the Royal College of Paediatrics and Child Health (Appendix 5).

The occupational therapy core group members were all practising therapists, educators or researchers. All group members undertook guideline development work in their own time, with some support from employers (for example to attend meetings).

Three individuals who were involved in neonatal research and practice were co-opted as additional appraisers.

All comments received from stakeholders, parents and end users on the draft scope and draft guideline document were reviewed by the Guideline Development Group. Where appropriate, revisions were incorporated into the scope form or guideline document prior to submission, for approval, to RCOT's Practice Publications Group. Conflict of interest declarations were noted and reviewed for any necessary action.

In the interests of openness and transparency, details of the comments submitted as part of the consultation activities are available on request from the Royal College of Occupational Therapists.

9.2 Stakeholder involvement

Stakeholders expected to have an interest in the guideline topic were identified by the core group membership at the preliminary guideline meeting. Specific attention was paid to identifying professional bodies that represent those working with infants and their parents, and national charitable or voluntary organisations that may represent people who access neonatal and early intervention services.

9.2.1 Scope consultation with stakeholders

A core group of stakeholders were approached to comment on an initial draft of the scope, which was provided in the form of a Stakeholder Information Document (together with a comments pro forma and conflict of interest declaration form).

The following stakeholders were invited to comment on the scope document:

Professional bodies: Royal College of Paediatrics and Child Health; Royal College of General Practitioners; Association of Paediatric Chartered Physiotherapists; Royal College of Speech

and Language Therapists (Neonatal Special Interest Group); Neonatal Nurses Association; British Association of Perinatal Medicine; British Association of Social Workers.

- Training Centres: Brazelton Centre UK; NIDCAP Centre UK.
- Charities: Bliss, National Autistic Society, SENSE, SCOPE, Best Beginnings.

Comments received were reviewed by the Guideline Development Group and, where these could be endorsed, the scope was amended accordingly.

9.2.2 Draft guideline consultation with stakeholders

The draft guideline was sent to each of the stakeholders who had been contacted as part of the scope consultation (Section 9.2.1) for their review and comment.

Feedback from additional stakeholders was also invited:

- Neonatal networks
- British Psychological Society
- Royal College of Nursing
- Royal College of Midwives
- Council of Occupational Therapists Educational Directors.

The guideline document and consultation form were placed in the public domain, for the one-month consultation period, on the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families webpage and RCOT's practice guideline webpage (12/12/16–13/01/17).

All comments were discussed at a meeting of the Guideline Development Group and taken into account during the revision of the final guideline.

9.3 Involvement of people who access services

9.3.1 Scope consultation with parents

Two parents identified by Guideline Development Group members were approached to provide comments on the scope. Comments received were reviewed by the Guideline Development Group and, where these could be endorsed, the scope was amended accordingly.

9.3.2 Draft guideline consultation with parents

Consultation activities with those who access services or lay people were undertaken to obtain views on the guideline recommendations and document. Parents were contacted through the Bliss network and the guideline group's own networks. One discussion group took place in early November in London, while a second was offered in Leeds (though feedback was ultimately given on paper due to parent unavailability). Additionally, parents who were unable to attend a discussion group were able to express their views via a semi-structured telephone interview.

To facilitate the discussion groups, the draft recommendations were provided prior to the discussion/interviews. This included a rationale for the guideline, the recommendations and an overview of the evidence. It also identified areas where parental feedback would be particularly valuable.

The Guideline Development Group recognised that the parents engaging in the consultation process would not necessarily be representative of all individuals with experience of neonatal occupational therapy services. However, overall the value of feedback provided by parents exceeded any concerns about representativeness.

All comments were duly considered for inclusion within the final guideline.

9.4 Occupational therapists' consultation

The primary target group of the guideline are occupational therapists and, specifically, those working in neonatal and early intervention services. Ongoing awareness of the progress of the guideline development project was communicated to the members of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families via their e-newsletter.

9.4.1 Scope consultation with occupational therapists

Members of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families were invited to participate in the scope consultation by the Specialist Section Chair via their membership email. Members of the Council of Occupational Therapy Education Directors and the Royal College of Occupational Therapists Neonatal Clinical Forum were also asked to participate. A copy of the scope documentation was provided with a request for feedback and comment.

Comments received were reviewed by the Guideline Development Group and, where these could be endorsed, the scope was amended accordingly.

9.4.2 Draft guideline consultation with occupational therapists

A one-month consultation period enabled members of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families to comment on a draft of the full guideline.

The consultation was additionally open to any member of the British Association of Occupational Therapists and was promoted via the monthly professional magazine, *OTnews*. The draft guideline and a consultation feedback and conflicts of interest form were made available to members (and the public) via the RCOT website.

All comments were duly considered for inclusion within the final guideline.

9.5 External peer review

Two independent peer reviewers were invited by the Guideline Development Group to critically appraise a draft of the full guideline. Reviewers were selected for their known clinical and research expertise in the field, and/or their guideline development experience or knowledge. The external peer reviewer form asked for comment on both the presentation and content of the draft guideline, taking into account factors such as its purpose, robustness and unbiased nature. The detailed views and expert opinions received were

discussed by the Guideline Development Group and used to inform the content of the final guideline.

9.6 Conflicts of interest

All Guideline Development Group members (core group and co-opted), stakeholders, end users and external peer reviewers were required to declare any pecuniary or non-pecuniary conflicts of interest, in line with the guideline development procedures (RCOT 2020).

Parents were also asked to verbally declare any particular conflicts of interest.

The nature of the potential or actual conflicts made in the declarations (Appendix 6) was not determined as being a risk to the transparency or impartiality of the guideline development.

9.7 Declaration of funding for the guideline development

This practice guideline was developed by a group led by a Specialist Section of the Royal College of Occupational Therapists. Specialist Sections are official branches of RCOT with specialist interests which, through their membership, are able to engage expert practitioners, educators and researchers in the development of guidelines, and access the required clinical and research expertise.

As a membership organisation, the major source of funding for the Royal College of Occupational Therapists and its Specialist Sections is the membership. Other sources of income are primarily advertising and events.

The development and publication of this practice guideline were funded by the Royal College of Occupational Therapists and the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families. The Royal College of Occupational Therapists provided specific resources to cover the meeting venue, travel expenses, literature search, and editorial and publication support. A small ring-fenced allocation was made by the National Executive Committee of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families to fund any other costs associated with the development and promotion of the practice guideline.

There were no external sources of funding.

The project lead, who chaired meetings, was a member of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families, but was not a National Executive Committee member so had no direct decision-making relationship with the allocated funding for the project.

The editorial leads for the guideline were the project lead and an officer at the Royal College of Occupational Therapists, who attended guideline meetings as an 'officer in attendance'. The recommendation statements and guideline content were developed and finalised by the Guideline Development Group with the involvement of stakeholders, parents, end users and external peer review. The views of the Royal College of Occupational Therapists have not, therefore, unduly influenced the final recommendations in this guideline.

9.8 Appraisal and ratification process

The guideline proposal, scope and final document were all reviewed and subsequently ratified by the Royal College of Occupational Therapists' Practice Publications Group, in line with the requirements of the *Practice guideline development manual*, fourth (RCOT 2020).

The scope was approved by the Practice Publications Group in December 2015 and the final version of this guideline was approved by the Practice Publications Group in April 2017.

10 Guideline methodology

10.1 Guideline question

What is the evidence to support occupational therapy in neonatal services and in early intervention?

The PICO framework (Huang et al 2006, Richardson et al 1995) was used to assist in developing the specific practice question further (Table 10.1). PICO describes the specific care group or condition being studied, and the nature of the intervention to be investigated. A comparative treatment can be specified where applicable, together with the anticipated outcomes (the desired/undesired or expected results of the intervention). This level of specificity is important in developing the question so that it addresses the requirements of the scope (RCOT 2020).

Table 10.1: PICO framework

Patient (person who accessed services), **P**opulation or **P**roblem/circumstance	Infants born preterm or born at term but deemed high risk, from birth to aged 2 years. Parents of high-risk infants.
Intervention under investigation or action	Occupational therapy interventions.
Comparison, which is an alternative intervention or action	None.
Outcome desired	Earlier discharge from an initial inpatient admission. Fewer readmissions. Increased parent confidence. Improved parent self-efficacy. Increased opportunities for parent engagement on the neonatal unit. Promotion of secure parent–infant relationship. Improved quality of interventions. Fewer do not attends (DNAs) in early intervention services due to the collaborative partnerships formed between parents and therapists. Earlier identification of emerging developmental concerns and implementation of appropriate early intervention services or referral to relevant specialist services.

10.2 Literature search strategy and outcomes

The literature search was carried out by the Royal College of Occupational Therapists' librarians, experts in the field of occupational therapy literature, using a search strategy defined following discussion and agreement with the Guideline Development Group. The search strategy involved two distinct searches: first, literature that was occupational therapy

specific, and second, a broader search on interventions used by, but not specific to, occupational therapy.

10.2.1 Key terms

The overall strategy involved combining concept groups of key words. Nine key categories or concepts and their related terms were identified: pure neonate terms, paediatric terms, population- and setting-related terms, interventions, related interventions, occupational therapy, occupational therapy-related terms, finance and value terms, and setting terms (Appendix 7, Table A7.1). The combination of strings searched aimed to identify the most relevant results to meet the requirements of the guideline scope.

Specific exclusions identified were material published pre-2000 (occupational therapy-specific literature) or pre-2006 (intervention-specific literature) and language other than English (due to lack of resources for translation). A ten-year time frame was identified as appropriate for the intervention-specific literature but given the perceived limited nature of the occupational-specific research in this area of practice, a 16-year time frame was agreed as appropriate to ensure inclusion of profession-specific seminal research.

10.2.2 Databases

The databases searched reflected the most likely sources of published peer-reviewed occupational therapy neonatal and early intervention evidence. Six core databases were searched from 1 January 2000 (occupational therapy specific) or 1 January 2006 (intervention specific) to the dates the individual searches were carried out (in 2016) as detailed in Table 10.2.

Table 10.2: Database searches

Core databases	Occupational therapy specific	Intervention specific
Cumulative Index to Nursing and Health Literature (CINAHL)	13/01/16 and 26/01/16	25/02/16 and 18/03/16
MEDLINE		
Allied and Complementary Medicine (AMED)	13/01/16, 15/01/16 and 26/01/16	No search undertaken
Social Policy and Practice		
Health Management Information Consortium (HMIC)		
PsycINFO		

Additional specialist databases were also searched: OTDBASE, OT SEARCH, OTSeeker, the Cochrane Library and the Royal College of Occupational Therapists Library online catalogue. Hand-searching was not systematically employed, but articles were included when brought to the attention of College officers or Guideline Development Group members.

Searches included title, abstract or descriptor fields. The date of each search, search fields and search result numbers are detailed in Appendix 7 (Tables A7 and A8). Full search histories are available on request from the Royal College of Occupational Therapists.

10.2.3 Search results

The search identified a total of 1,139 results related to occupational therapy. These were scrutinised for duplicates, both within-database searches and cross-database search returns, by the Royal College of Occupational Therapists' Research and Development Officer. A total of 549 duplicates were removed.

Additionally, a separate search for intervention-specific literature returned 2,531 results. After searching for duplicates within and across databases, 1,627 were removed.

The unique results lists from both searches were provided to the project lead and Guideline Development Group member undertaking the screening activity.

10.3 Criteria for inclusion and exclusion of evidence

The resultant 590 occupational therapy-related and 904 intervention-specific search findings (title and abstracts) were each independently screened by two different members of the Guideline Development Group against an eligibility checklist:

- Inclusion criteria:
  - Infants from birth to 2 years.
  - Occupational therapy specific and relevant.
  - Research.
  - Relevant to guideline question.
- Exclusion criteria:
  - Descriptive or contextual articles.

While one article was co-authored by one of the screeners, a second reviewer ensured no undue bias. Where the screeners had a yes/no variation in opinion as to whether an abstract should be included or excluded for appraisal, the abstract was further reviewed against the eligibility criteria by the reviewers to come to a consensus decision.

This process enabled the identification of abstracts that would be potentially relevant to the practice guideline and should therefore be included within the critical appraisal process.

10.3.1 Occupational therapy-specific literature results

Following the screening, 438 occupational therapy-specific items were further excluded, resulting in a total of 152 items identified for full paper review and critical appraisal.

During the critical appraisal process, 24 articles were identified as inappropriate because they were out of scope, resulting in 128 articles which were fully critically appraised and details transferred into evidence tables (see Section 11.6); 52 items of evidence were subsequently used in developing the recommendations (see Section 10.5).

An overview of the occupational therapy-specific literature search outcomes is provided in Figure 10.1.

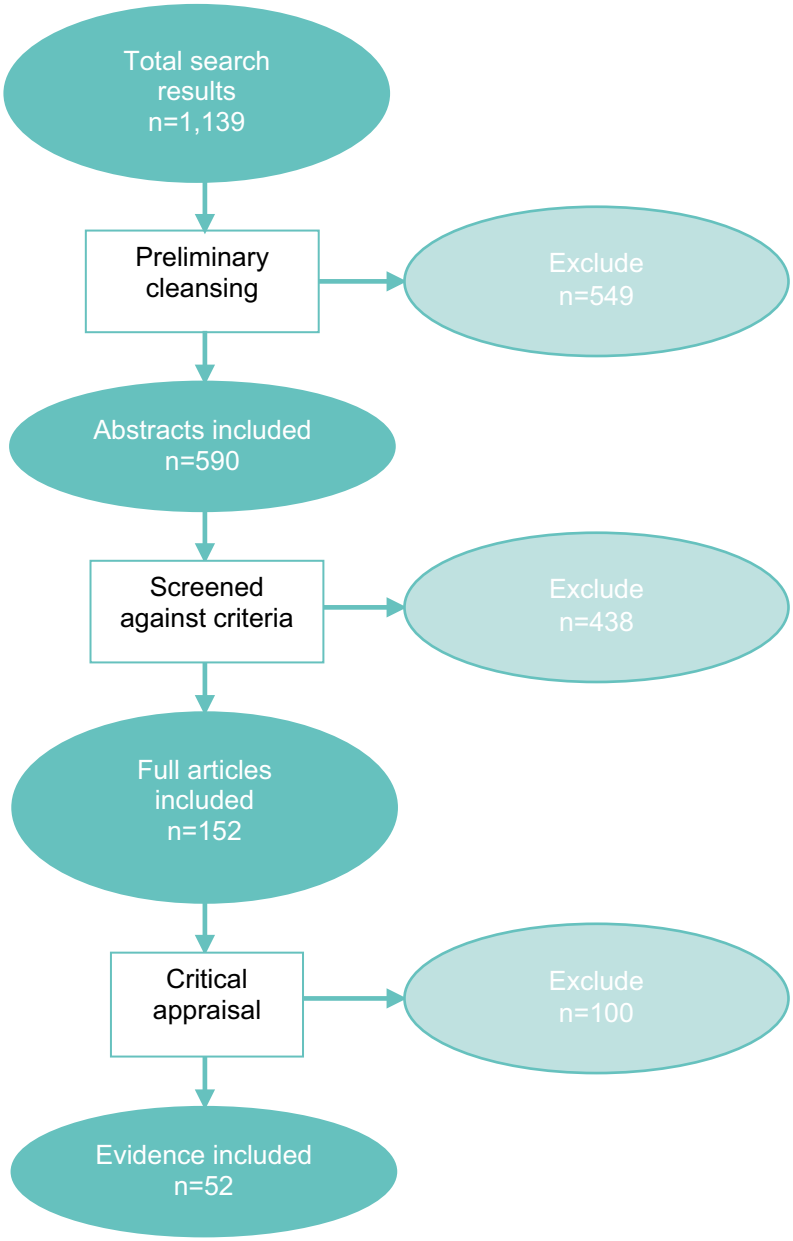


Figure 10.1 Occupational therapy-specific literature search outcomes

10.3.2 Intervention-specific literature results

After screening the intervention-specific literature, a total of 148 articles were identified as relevant (Figure 10.2). However, given the guideline's focus is only occupational therapy, the Guideline Development Group agreed these results would be used as further evidence if the occupational therapy-specific literature was not felt to provide a substantive enough evidence base. Once the occupational therapy-specific literature had been appraised and discussed, the Guideline Development Group agreed that literature relating to the following topics would also be appraised: assessment, feeding, pain management, infant positioning and skin-to-skin contact. The guideline development lead categorised the

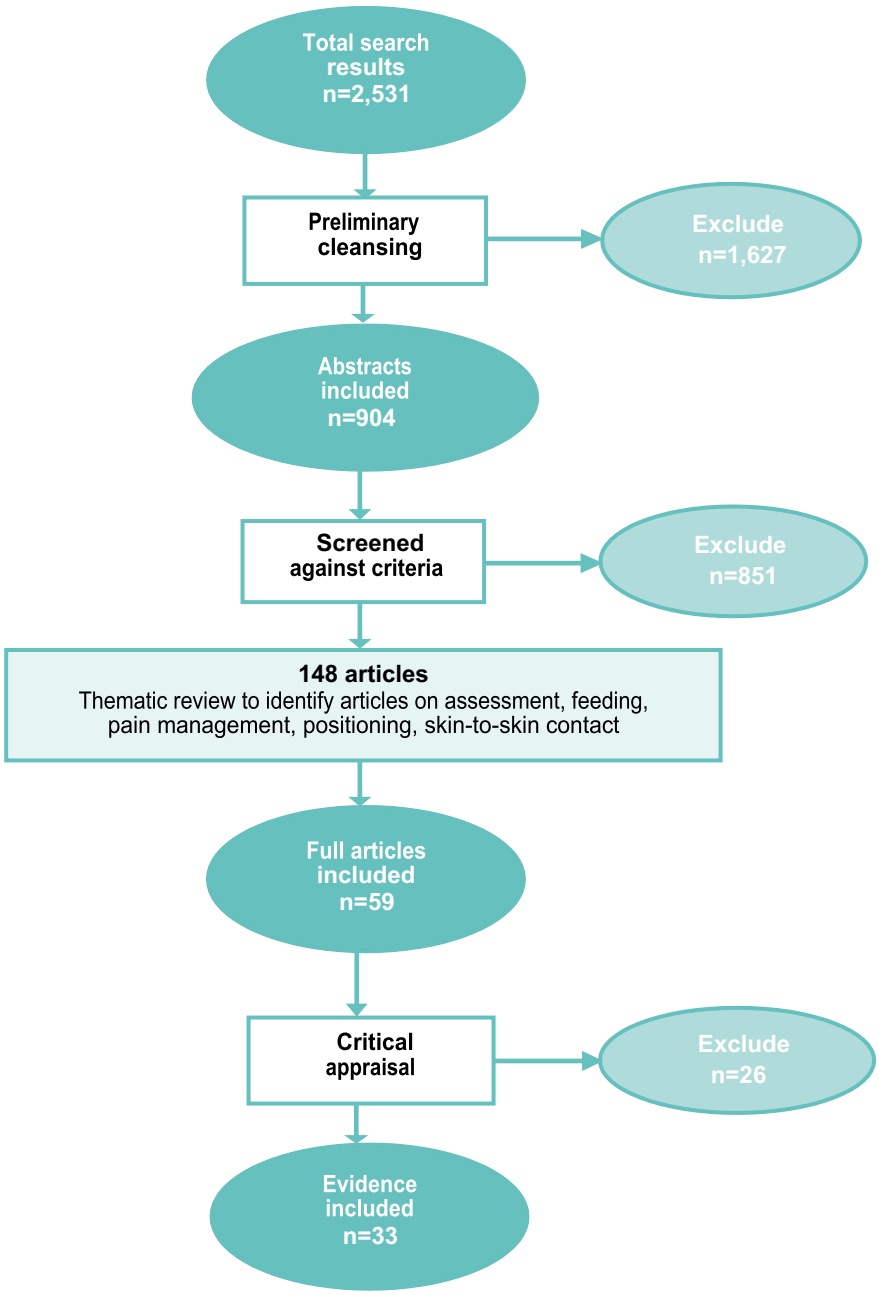


Figure 10.2 Intervention-specific literature search outcomes

intervention-specific literature, resulting in 59 articles for appraisal. During the appraisal process, six were identified as out of scope, resulting in 53 which were fully critically appraised and whose details were transferred into evidence tables.

10.4 Strengths and limitations of body of evidence

Each of the 181 articles identified as potential evidence was critically appraised by two independent reviewers. Appraisals were undertaken by all members of the Guideline Development Group, with additional support provided by co-opted members. The allocation process ensured that reviewers did not appraise any evidence that they had authored or co-authored. Any discrepancy in grading was discussed and the final grading agreed and confirmed via group consensus.

The quality of the evidence was initially assessed and recorded using forms based on the Critical Appraisal Skills Programme (CASP) checklists (CASP 2013). Assessment took into account factors such as the appropriateness of the study design and recruitment strategy, procedural rigour in data collection and analysis, confounding factors and potential biases, transferability, precision of results and the value of the findings.

A quality of evidence grade was then assigned to each individual article using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach, as defined within the *Practice guideline development manual*, fourth edition (RCOT 2020). The grading reflects the research design and the confidence in the research findings.

The initial grading was allocated as follows:

- Randomised controlled trial (RCT)/systematic review = High.
- Observational study = Low.
- Any other evidence = Very low.

Limitations in the design of a study or its implementation may, however, bias the estimates of the treatment effect. If there were serious limitations, then downgrading of the quality of the evidence was considered, as in Table 10.3.

Table 10.3: Grading evidence up or down (after GRADE Working Group 2004)

Decrease grade if	• Serious or very serious limitation to study quality. • Important inconsistencies in results. • Some or major uncertainty about directness of the evidence. • Imprecise or sparse data (relatively few participants and/or events). • High probability of reporting bias. **Each quality criterion can reduce the quality by one or, if very serious, by two levels.**
Increase grade if	• Magnitude of the treatment effect is very large and consistent. • Evidence of a large dose–response relation. • All plausible confounders/biases would have decreased the magnitude of an apparent treatment effect. **Only studies with no major threats to validity should be upgraded.**

A decision to increase or decrease the initial grade of the evidence was recorded and justified on the critical appraisal forms. A moderate category became relevant only if there was a suggested change in the initial grading of an article due to upgrading or downgrading. Evidence was ultimately graded in one of four categories as detailed in Table 10.4.

If there was no reason to upgrade or downgrade the evidence, then the original grading remained.

Table 10.4: GRADE quality of evidence grading (after GRADE Working Group 2004)

Quality of evidence	Grading	Characteristics	Confidence
High	A	Based on consistent results from well-performed randomised controlled trials, or overwhelming evidence of an alternative source, e.g. well-executed observational studies with strong effects.	True effect lies close to that of the estimate of the effect. Further research is very unlikely to change confidence in the estimate of the effect.
Moderate	B	Based on randomised controlled trials where there are serious flaws in conduct, inconsistency, indirectness, imprecise estimates, reporting bias or some other combination of these limitations, or from other study designs with special strengths.	True effect likely to be close to the estimate of the effect but the possibility that there could be a substantial difference. Further research is likely to have an important impact on confidence in the estimate of effect and may change the estimate.
Low	C	Based on observational evidence, or from controlled trials with several very serious limitations.	True effect may be substantially different from the estimate of the effect. Further research is very likely to have an important impact on confidence in the estimate of the effect and is likely to change the estimate.
Very low	D	Based on case studies or expert opinion.	Any estimate of effect is very uncertain and may be far from the true effect.

Once the methodological quality of each piece of evidence was assessed, details for each item of evidence were collated, from the two independent appraisals, into an evidence table (Appendix 2).

10.5 Method used to arrive at recommendations

The evidence tables were used by the Guideline Development Group to synthesise the evidence available, and as the basis to evaluate and judge the potential contribution of each item of evidence to the development of the guideline recommendations.

The evidence tables were grouped in categories identified by the guideline project lead, and these were used as the starting point for developing recommendations.

Once a recommendation had been developed, an overall quality of evidence rating was determined. This overall rating was established as follows:

- Where the evidence outcomes pointed in different directions towards benefit and towards harm, the lowest quality of evidence determined the overall quality grade of evidence.
- Where the outcomes pointed in the same direction towards either benefit or harm, the highest quality of evidence was appropriate to recommend an intervention and determined the overall quality of evidence.
- In circumstances where the balance of benefits and harm was uncertain, the lowest grade of quality of evidence was assigned.

Strength of recommendation was the second element of the GRADE system applied, using the categories 'strong' or 'conditional' to reflect the strength (Table 10.5).

Table 10.5: Strength of grade (after Guyatt et al 2008)

Strength	Grade	Benefits and risks	Implications
Strong	**1** **'It is recommended ...'**	Benefits appear to outweigh the risks (or vice versa) for the majority of the target group.	Most people who access services would want or *should* receive this course of intervention or action.
Conditional	**2** **'It is suggested ...'**	Risks and benefits are more closely balanced, or there is more uncertainty in likely service user values and preferences.	The majority of people who access services would want this intervention but not all, and therefore they should be supported to arrive at a decision for intervention consistent with the benefits and their values and preferences.

The development of the recommendations, including assignment of the overall quality and strength grading, was a consensus decision obtained at the Guideline Development Group meeting, and by subsequent email correspondence as required for any revisions. There were no recommendations that were not agreed by all members, so that no formal voting system was required. Eighty-five items of evidence were used to develop the recommendations.

A recommendation decision form was completed for each recommendation developed. This recorded key information about the evidence used to form the basis of that recommendation, the overall allocation of the quality of evidence and strength of the recommendation. The form also facilitated discussion and recording of any specific or associated risks and benefits, and this was reflected in the final strength of recommendation. Any judgement by the Guideline Development Group was documented as part of this decision-making process (the forms are available on request from the Royal College of Occupational Therapists).

11 Guideline review process – second edition

The guideline review commenced in 2020, three years after publication of the guideline, and followed the review process as outlined in the *Practice guideline development manual*, fourth edition (RCOT 2020, Section 3.14).

The guideline question, objective and scope were unchanged, as were the criteria for inclusion or exclusion of evidence. This section outlines the process followed and, where necessary, cross-references the first edition development process and methodology.

11.1 Guideline Review Group established

The Guideline Review Group consisted of eight members of the original Guideline Development Group and five new members. Ten were occupational therapists with expertise and specialist interest in occupational therapy in neonatal and early intervention, and one fulfilled the role of Equality and Diversity Representative. One was a representative of the Royal College of Paediatrics and Child Health, and one was a representative of the British Association of Perinatal Medicine. One member was a public contributor with experience as the mother of a high-risk infant. Conflicts of interest were declared in line with the guideline development process requirements.

11.2 Identification of new evidence

Monitoring searches were carried out in 2018 and 2019 to ensure no significant studies were published which would require an immediate change to the recommendations or withdrawal of the guideline. All searches were undertaken by the RCOT Library and Information Service.

11.2.1 Key search terms

The monitoring searches (2018 and 2019) replicated the first edition guideline search terms for the occupational therapy-specific searches. These searches involved combining groups of search terms from eight categories or concepts and their related terms: neonate, paediatric, population, intervention, setting, occupational therapy and related, and finance/value terms (Appendix 8 Tables A8.1 and A8.2).

The full review search strategy replicated the first edition guideline search terms across both the occupational therapy-specific search and the intervention-specific search.

11.2.2 Databases

The yearly monitoring searches were only carried out on the EBSCOHOST and Ovid platforms. For the full review search, core and specialist databases were searched from the last date of the first edition guideline search to the date the search was carried out (January–March 2016 to November 2020). The databases accessed for the occupational therapy-specific search included: EBSCOHOST platform (MEDLINE, CINAHL); Ovid platform (AMED, HMIC, APA PsycINFO, Social Policy and Practice); OTseeker; OTDBASE; OT SEARCH; and Cochrane Library. For the intervention-specific search, the following

databases were accessed: EBSCOHOST platform (MEDLINE, CINAHL); and Ovid platform (AMED, HMIC, APA PsycINFO, Social Policy and Practice).

Details for the specific database searches, including when they were searched, are provided in Appendix 8 Tables A8.3–A8.5.

11.2.3 Search results

The monitoring searches undertaken in 2018 and 2019 returned 188 results (EBSCOHOST platform n=174 and OVID platform n=14). The RCOT officer cleansed for duplicates and anomalies within and across databases, resulting in 117 articles for screening. No articles were identified as presenting evidence that any recommendations should be changed to prevent harm.

For the full occupational therapy-specific search undertaken in November 2020, the core and specialist searches produced a total of 427 results (EBSCOHOST platform n=211; Ovid platform n=21; and specialist databases/websites n=195). Following cleansing, 157 abstracts were suitable for screening.

The intervention-specific search was also undertaken in November 2020. This search resulted in 1,445 results (EBSCOHOST platform n=1,334; Ovid platform n=111). A total of 935 abstracts were suitable for screening after cleansing.

11.2.4 Screening and appraisal of evidence

Abstracts from the 2018 and 2019 monitoring searches were screened by two members of the original Guideline Development Group and 26 articles were suitable for appraisal. A quarter of the 157 (n=48) occupational therapy-specific abstracts were independently screened by two occupational therapist members of the Guideline Review Group against criteria identified in the guideline development process (Section 10.3). The remaining abstracts were screened against the criteria by one occupational therapist member. In total, the full search screening resulted in 211 occupational therapy-specific items being excluded, and 63 items of evidence being selected for independent appraisal by two group members.

An overview of the occupational therapy-specific literature search is provided in Figure 11.1.

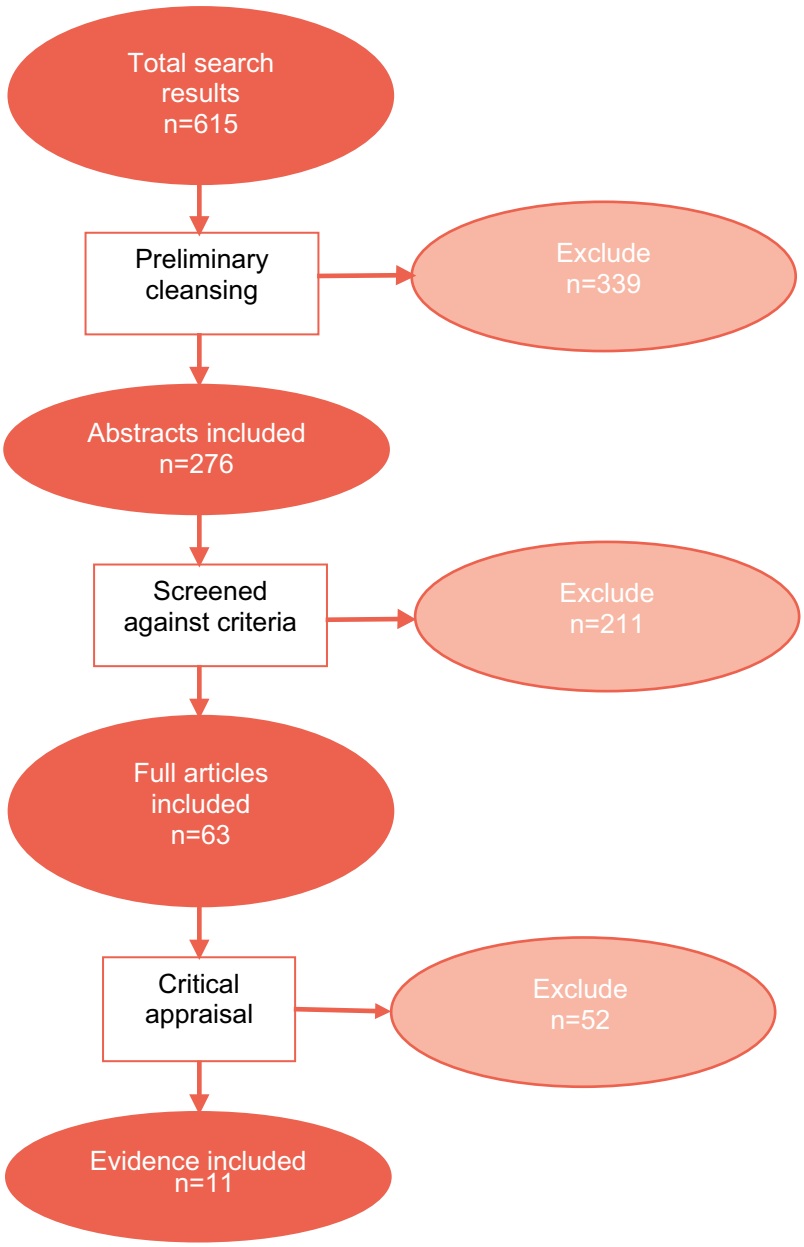


Figure 11.1 Occupational therapy-specific literature results

Of the 1,445 intervention-specific abstracts, 510 were removed after preliminary cleansing, and of those remaining, a quarter (n=276) were independently screened by two occupational therapist members of the Guideline Review Group, while the rest were screened by one occupational therapist member. After screening, 594 articles were excluded. The remaining articles were discussed by the full guideline group, and after a further screening to ensure relevance to occupational therapy, 98 articles remained to appraise.

An overview of the intervention-specific literature search is provided in Figure 11.2.

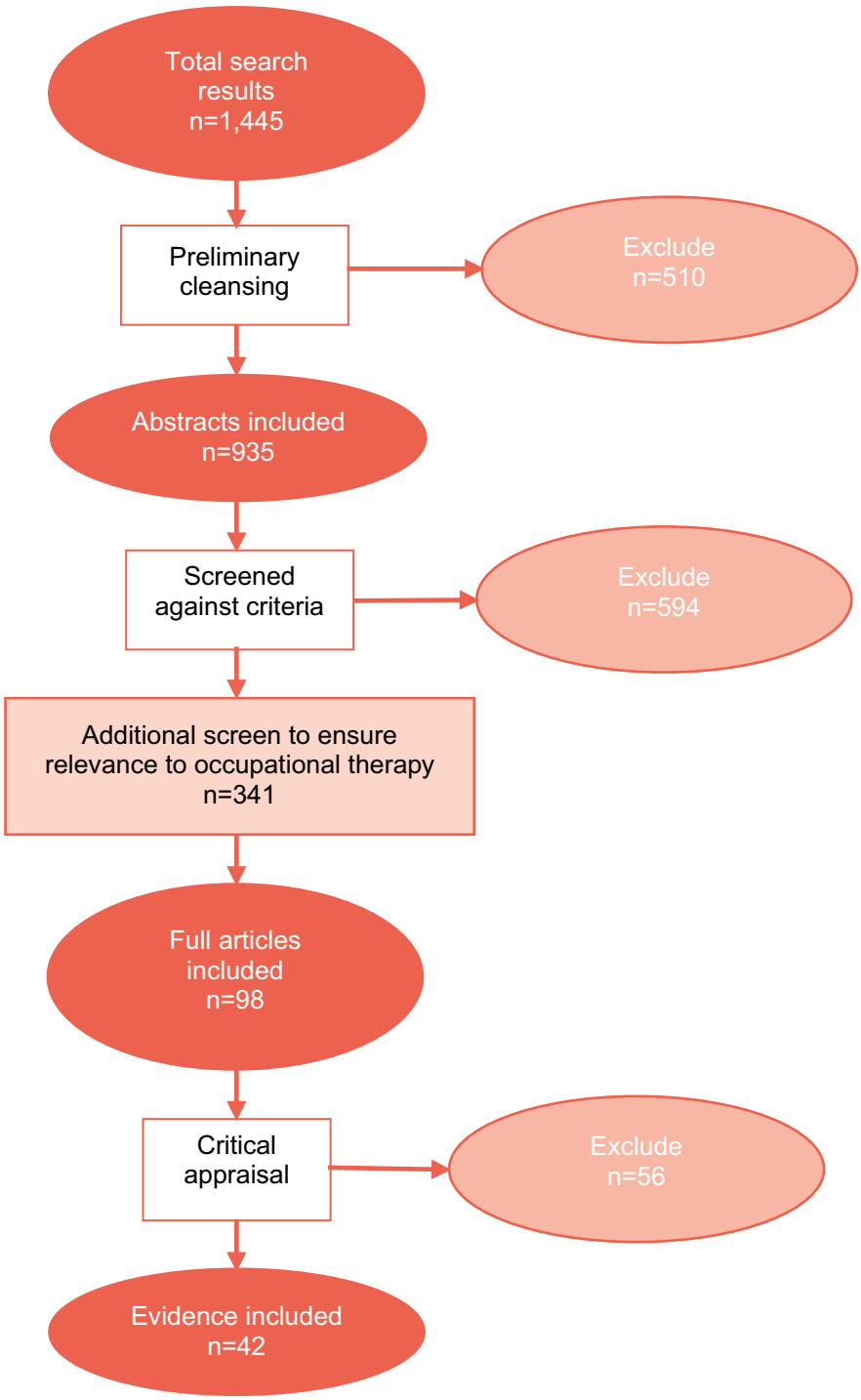


Figure 11.2 Intervention-specific literature results

11.3 Assessment of update requirements

A total of 53 articles were agreed by the group as providing new evidence for inclusion in an update of the guideline, supporting five new recommendations and revisions to 20 existing recommendation statements.

The 53 new items of evidence were mostly graded as low (Grade C, n=19) or high (Grade A, n=17). Fourteen were graded as moderate (Grade B, n=14) and only three as very low (Grade D, n=3).

The Guideline Review Group's discussions focused on the update required for the second edition in terms of:

- new evidence appraised
- development of recommendations where indicated by new evidence or knowledge
- consideration of any original material that was no longer appropriate and how this might need to be replaced or withdrawn
- consideration of any relevant feedback and comments received since the publication of the guideline.

11.4 External review

A consultation of the revised draft guideline was held with stakeholders, members of the public and occupational therapists between 19 November and 17 December 2021. Where permission was given, those who participated are listed in the acknowledgements (Appendix 9).

Occupational therapists: The draft updated guideline was made available for review to occupational therapists, particularly members of the RCOT Specialist Section – Children, Young People and Families. All members were alerted to the consultation via the professional body's magazine *OTnews* and via social media.

Stakeholders: Stakeholders invited to participate in the original consultation were contacted and invited to provide any comments on the updated version of the guideline along with new stakeholders identified by Guideline Review Group members. New stakeholders included the following:

- The Smallest Things (Scottish Neonatal Network)
- The Disabled Children's Partnership.

Parents: An online survey, approved through RCOT's governance process, was targeted at parents of infants born high risk. The survey, comprised of 16 questions, was available via JISC Online Surveys, a GDPR-compliant platform. It was promoted by organisations with relevant audiences such as Bliss and Tiny Lives, and via the Guideline Development Group's networks. Twenty-seven parents responded to the survey.

Peer review: Two peer reviewers, experienced in both the topic and research, were identified to carry out an independent peer review of the updated draft.

11.5 College appraisal and ratification process

A draft of the second edition of the guideline was submitted to the RCOT Publications Group for review and was approved in 5 May 2022.

11.6 Overview of limitations and any potential bias of the guideline

Evidence included in the development of the guideline recommendations was sourced from published, peer-reviewed journal articles. Relevant policy documents or grey literature have been referenced within the contextual information where applicable.

The literature search identified a body of primary research relating to practices and interventions that are provided in the neonatal and early intervention settings by occupational therapists. The outcome of the literature search, appraisal and synthesis of the evidence resulted in 138 papers being used to support the guideline recommendations.

A total of 53% of the evidence was derived from studies of high or moderate quality:

Grade A = 33% (n=46)

Grade B = 20% (n=28)

Grade C = 38% (n=52)

Grade D = 9% (n=12)

The Guideline Development Group downgraded 35 of the studies, initially graded A or C, due to limitations identified from the appraisal and a resultant lack of confidence in the estimate of the research effect. Six studies were upgraded due to their specific strengths in the study design. These decisions and comments on individual studies are noted in the evidence tables (see Appendix 2).

A summary of the evidence used to develop the recommendations is provided in Table 11.1.

Table 11.1: Summary of evidence used to develop the recommendations

Topic area	Author	Year	Evidence quality
Occupation-based assessment	Als et al	2003	A
	Craciunoiu and Holstii	2017	A
	Pineda et al	2020	B
	Bartlett	2003	C
	El-Dib et al	2011	C
	Sucharew et al	2012	C
	Allinson et al	2017	D
	Crowle et al	2015	D
	Liu et al	2010	D

Topic area	Author	Year	Evidence quality
Developmental care	Als et al	2003	A
	McAnulty et al	2009	A
	Pineda et al	2017	A
	Symington and Pinelli	2006	A
	Symington and Pinelli	2002	A
	Legendre et al	2011	B
	McAnulty et al	2010	B
	Oostlander et al	2019	B
	Soleimani et al	2020	B
	Wallin and Eriksson	2009	B
Pain management	Axelin et al	2006	A
	Ferber and Makhoul	2008	A
	Franck et al	2011	A
	Johnston et al	2011	A
	Zargham-Boroujeni et al	2017	A
	Cong et al	2012	B
	Hatfield et al	2020	B
	Obeidat et al	2009	B
	Franck et al	2012	C
	Gibbens et al	2015	C
	Kostandy et al	2008	C
	Orovec et al	2019	C
	Richardson et al	2020	C

Topic area	Author	Year	Evidence quality
Skin-to-skin (kangaroo) care	Boo and Jamli	2007	A
	Cong et al	2009	A
	Cunningham et al	2018	A
	Gathwala et al	2008	A
	Hake-Brooks and Anderson	2008	A
	Ludington-Hoe et al	2004	A
	Morelius et al	2015	A
	Mu et al	2020	A
	Vittner et al	2018	A
	Cho et al	2016	B
	Head	2014	B
	Vittner et al	2019	B
	Bloch-Salisbury et al	2014	C
	Blomqvist et al	2013	C
	Carbasse et al	2013	C
	Kostandy et al	2008	C
Touch	Asadollahi et al	2016	B
	Shoghi et al	2018	B
	Afand et al	2017	C
	Baniasadi and Hosseini	2019	C
	Lotfalipour et al	2019	C
	Kim et al	2017	C
	Elsagh et al	2019	D

Topic area	Author	Year	Evidence quality
Postural support	Lai et al	2016	A
	Kochan et al	2019	B
	Madlinger-Lewis et al	2015	B
	Santos et al	2017	
	Gouna et al	2013	C
	Grenier et al	2003	C
	Liaw et al	2012	C
	Nakano et al	2010	C
	Zarem et al	2013	C
	Coughlin et al	2010	D
Infant feeding	Ross and Browne	2013	B
	Brown et al	2007	C
	Caretto et al	2000	C
	Flacking et al	2013	C
	Maguire et al	2018	C
	Mitha et al	2019	C
	Pickler et al	2013	C
	Swift and Scholten	2010	C
	Ward et al	2000	C
	Chrupcala et al	2015	D
	Waitzman et al	2014	D
Parent engagement	Ding et al	2019	A
	Gibbs et al	2015	A
	O'Brien et al	2018	A
	Aydon et al	2018	B

Topic area	Author	Year	Evidence quality
	Dür et al	2018	B
	Bäcke et al	2020	C
	Cardin	2020	C
	Chiarello et al	2006	C
	Dudek-Shriber	2004	C
	Fucile et al	2020	C
	Gibbs et al	2016	C
	Gund et al	2013	C
	Gustafson et al	2016	C
	Harrison et al	2007	C
	Ingram et al	2016	C
	Kadlec et al	2005	C
	Pineda et al	2018	C
	Ganadaki and Magill-Evans	2003	D
	Price and Miner	2009	D
	Skene et al	2019	D
	Winston	2015	D
Parent support	Dol et al	2017	A
	Evans et al	2014	A
	Kasparian et al	2019	A
	Månsson et al	2019	A
	Melnyk et al	2006	A
	Melnyk et al	2001	A
	Milgrom et al	2019	A
	O'Brien et al	2018	A

Topic area	Author	Year	Evidence quality
	Petteys and Adoumie	2018	A
	Thomson et al	2020	A
	White-Traut et al	2013	A
	Zelkowitz et al	2011	A
	Askary Kachoosangy et al	2020	B
	Dür et al	2018	B
	Gramszlo et al	2020	B
	Matricardi et al	2013	B
	Bäcke et al	2020	C
	Mouradian et al	2013	C
	Nassef et al	2020	C
	Suarez et al	2018	C
Identifying developmental concerns	Bröring et al	2017	A
	Maitra et al	2014	A
	Bigsby et al	2011	B
	Witt Mitchell et al	2015	B
	Crozier et al	2016	C
	Fewell and Claussen	2000	C
	Magill-Evans et al	2002	C
	Pineda et al	2015	C
	Sajaniemi et al	2001	C
	Watkins et al	2014	C
Early intervention	Hughes et al	2016	A
	Leskulchai and Cole	2001	A
	Orton et al	2009	A

Topic area	Author	Year	Evidence quality
	Spencer-Smith et al	2012	A
	Spittle et al	2015	A
	Spittle et al	2007	A
	Duncan et al	2020	B
	Hwang et al	2013	B
	Gmmash and Effgen	2019	C
	Hintz et al	2008	C
	Stark et al	2020	C
	Ideishi et al	2010	D

The role of the Royal College of Occupational Therapists and the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families in the development and authoring this practice guideline is fully acknowledged (see Section 9.7).

The potential for any bias in development and authoring was, however, minimised through the rigorous nature of the guideline development process. This was achieved through the systematic methodology adopted, the contributions of stakeholders and parents, the valued opinions of the external peer reviewers and occupational therapists, and the judicious management of any potential or actual conflicts of interest.

12 Updating the guideline

The National Executive Committee of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families is responsible for monitoring new evidence over the next five-year period and will provide a focal point for feedback received following publication of the second edition of the guideline.

If you would like to provide feedback on the guideline or implementation tools, please go to https://www.rcot.co.uk/about-us/specialist-sections/children-young-people-and-families-rcot-ss/ contacts-and-committee for up-to-date contacts for the Specialist Section.

In line with RCOT's procedures, this second edition of the guideline will be available until 2027 and then will be withdrawn; however, relevant literature will be monitored yearly up to 2027 to detect new evidence that may have a significant impact on the recommendations. If this occurs, and depending on the strength of the evidence, the guideline may be withdrawn earlier. There will be no further updates to this guideline.

Appendix 1: Glossary and abbreviations

APIB	**Assessment of Preterm Infant Behavior** A neurobehavioural assessment of preterm and full-term newborns aligned to the NIDCAP.
ATVV	**Auditory Tactile Visual Vestibular intervention** This is an approach used primarily in the USA that includes step-by-step instructions on how to introduce the sensory stimuli in a specific order to a premature baby. It involves the use of voice (auditory), massage (touch), eye contact (visual) and rocking (vestibular).
Attunement	'Attunement refers to an empathic sharing of emotions between parents and their infant. Parents and infants are not attuned at all times and it is through healthy "ruptures" followed by "repairs" to attunement that learning about interaction and the regulation of emotions and behaviour takes place within the context of the developing parent–infant relationship' (Royal College of Midwives 2020, p23)
Autistic spectrum disorder/autism (ASD)	'Autism is a lifelong developmental disability that affects how people communicate and interact with the world. One in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK.' http://www.autism.org.uk/autism
BAOT	**British Association of Occupational Therapists** BAOT is the professional body for all occupational therapy staff in the UK. https://www.rcot.co.uk/about-us/governance/how-we-are-run
Bliss	A registered charity supporting babies born premature or sick to receive the best care in the UK. They achieve this through supporting families, campaigning for change and supporting professionals, and enabling life-changing research. https://www.bliss.org.uk/about-us/about-bliss
Bliss Baby Charter	The Bliss Baby Charter is a practical framework for neonatal units to self-assess the quality of family-centred care they deliver against a set of seven core principles. It enables units to audit their practices and develop meaningful plans to achieve changes that benefit babies and their families. With the Bliss Baby Charter, units are given a clear focus that is based on, and supports, national standards. https://www.bliss.org.uk/health-professionals/bliss-baby-charter

BSID	**Bayley Scales of Infant Development** Standardised assessment of development used widely in research. The most recent version is the BSID III which is comprised of five sections: cognitive, expressive and receptive language, fine and gross motor. Used from birth to 42 months.
CASP	**Critical Appraisal Skills Programme** The Critical Appraisal Skills Programme supports the development of skills in the critical appraisal of scientific research, and provides a number of critical appraisal tools to support this activity. (CASP 2013) http://www.casp-uk.net
Cerebral palsy	'Cerebral palsy is a condition that affects muscle control and movement. It affects about 1 in every 400 children in the UK. It is usually caused by an injury to the brain before, during or after birth, but there may be no obvious single reason.' https://www.scope.org.uk/advice-and-support/cerebral-palsy-introduction/
CI	**Confidence interval** 'A way of expressing how certain we are about the findings from a study, using statistics. It gives a range of results that is likely to include the "true" value for the population. A wide confidence interval (CI) indicates a lack of certainty about the true effect of the test or treatment – often because a small group of patients has been studied. A narrow CI indicates a more precise estimate (for example, if a large number of patients have been studied). 'The CI is usually stated as "95% CI", which means that the range of values has a 95 in a 100 chance of including the "true" value. For example, a study may state that "based on our *sample* findings, we are 95% certain that the 'true' population blood pressure is not higher than 150 and not lower than 110". In such a case the 95% CI would be 110 to 150.' Glossary: http://www.nice.org.uk/website/glossary/glossary.jsp
CLD	**Chronic lung disease** Previously known as bronchopulmonary dysplasia (BPD), this refers to an oxygen requirement at 28 days of age, characteristic lung changes on x-ray and an oxygen requirement at 36 weeks' gestational age.
Co-occupation	Co-occupations are caregiving activities in which parents and infants actively engage that address infant needs but also support the developing parent–infant relationship (including positive touch, nurturing, feeding, bathing and early reciprocal interaction).
Cognitive performance	Cognitive performance refers to a range of mental abilities, including learning, thinking, reasoning, remembering, problem solving, decision making, and attention. https://www.sciencedirect.com/topics/psychology/cognitive-functioning

Corrected gestational age	The baby's age calculated from the due date and used for all aspects of development until the child is 24 months' corrected age.
Developmental delay	'When a child takes longer to reach certain development milestones than other children their age. This might include learning to walk or talk, movement skills, learning new things, and interacting with others socially and emotionally.' https://www.mencap.org.uk/learning-disability-explained/conditions/global-development-delay#:~:text=The%20term%20'developmental%20delay'%20or,with%20others%20socially%20and%20emotionally.
Developmentally supportive care	Term that refers to the use of strategies that are 'derived from neurodevelopmental, environmental and human sciences to improve the potential of infants who are disadvantaged by premature birth or adverse perinatal events'. (Warren and Bond 2010, p14)
Dysphagia	Difficulty in swallowing.
Early intervention	Identification of infants and families at risk of developmental difficulties and provision of appropriate intervention.
EEG	**Electroencephalography** A method to record electrical activity in the brain using electrodes positioned on the skull.
ELBW	**Extremely Low Birthweight** Birthweight of less than 1000g (2 pounds 3 ounces) regardless of gestational age.
Facilitated tucking	Supporting the baby to be in a flexed position with arms and legs tucked up towards the torso.
FINE	**Family and Infant Neuro-developmental Education (FINE)** An education programme for healthcare professionals that consists of three levels of training; available in the UK and used throughout Europe. Level One is accredited through the Royal College of Nursing. http://www.bliss.org.uk/fine
Functional motor skills	Functional motor skills are voluntary movements that require both motor and sensory input to be successful and reflect all of the body's functions, activities and participation (Crepeau et al 2009, p688–689). Examples of functional motor skills in infants and young children include crawling/walking, exploring toys with hands and mouth, and feeding.
Gavage feeding	Feeding an infant directly into the stomach using an orogastric (through the mouth) or nasogastric (through the nose) tube. This is the accepted way to feed a premature or sick baby when they are not able to participate in oral feeding.

Gestational age	'The age of the fetus or newborn, usually expressed in weeks dating from the first day of the mother's last menstrual period.' (Anderson 2002)
GRADE	**Grading of Recommendations Assessment, Development and Evaluation** GRADE is a systematic and explicit methodology to assist in the judgement of the quality and strength of guideline recommendations. http://www.gradeworkinggroup.org
HIE	**Hypoxic ischaemic encephalopathy** A brain injury caused by oxygen deprivation to the brain, also commonly known as intrapartum asphyxia. It is the cause of death and severe impairment among infants. It is more common in term infants. https://www.cerebralpalsy.org/about-cerebral-palsy/cause/hypoxic-ischemic-encephalopathy
High risk	For the purpose of this guideline, high-risk infants include all infants born prematurely as well as term infants with neonatal encephalopathy, neonatal abstinence syndrome, neurological abnormalities, congenital conditions or who have undergone complex surgical procedures.
IVH	**Intraventricular haemorrhage** Graded I, II, III or IV. An IVH involves the germinal matrix, the immature capillary network, which overlies the head of the caudate nucleus. The haemorrhage may be confined to the germinal matrix, may extend into the ventricle or involve the parenchyma. An IVH usually occurs within 72 hours of birth. The germinal matrix disappears at about 32 weeks' gestation so haemorrhage is uncommon beyond this gestation. Grade I: isolated germinal matrix haemorrhage Grade II: IVH without ventricular dilatation Grade III: IVH with acute ventricular dilatation Grade IV: parenchymal haemorrhage venous infarct
Kangaroo care/SSC	Refers to the practice of holding a baby with skin-to-skin contact between the baby's chest and mother/father's chest. Uses principles from kangaroo mother care, which has three components: skin-to-skin contact, exclusive breastfeeding and support for the mother–infant dyad. http://www.skintoskincontact.com/an-introduction.aspx
LBW	**Low birthweight** Birthweight of less than 2.5kg (5 pounds 8 ounces) regardless of gestational age.

Moderate to late preterm	Infants born between 32 and 37 weeks' gestational age.
Neonatal abstinence syndrome (NAS)	A behavioural pattern of irritability, tremulousness and inconsolability exhibited in newborns exposed to addictive opiate drugs. (Anderson 2002)
Neonate	An infant under 28 days of life. https://www.bliss.org.uk/parents/in-hospital/about-neonatal-care/words-you-might-hear-on-the-neonatal-unit
Neurobehavioural organisation	Neurobehavioural organisation refers to the ability of the infant to organise and regulate themselves in reciprocal interaction with their caregiving environment, in order to facilitate the emergence of a hierarchy of co-ordinated neurobehavioural systems. These systems include autonomic/physiologic regulation, motor regulation, state organisation and social interaction. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2573022/
Neurobehavioural state	This is the level of alertness of the infant and can be divided into six separate states: deep sleep, light (or REM sleep), drowsy, quiet alert, active alert and crying. The state of the infant is related to how they are able to block out external stimuli in order to be able to interact with the world. (Brazelton and Nugent 1995)
Neurodevelopment	Neurodevelopment refers to the organisation and function of the central nervous system (CNS). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6899448/
Neuroplasticity	The brain's ability to reorganise itself by forming new neural connections throughout life. Neuroplasticity allows the neurons (nerve cells) in the brain to compensate for injury and disease and to adjust their activities in response to new situations or to changes in their environment.
NHS	**National Health Service** The NHS refers to the publicly-funded healthcare systems in the UK.
NICE	**National Institute for Health and Care Excellence** NICE (formerly the National Institute for Health and Clinical Excellence) provides national guidance and advice to improve health and social care. http://www.nice.org.uk

NICU Levels I, II and III	**Neonatal unit levels** • **Neonatal intensive care unit (NICU)** – This is the highest level of care and is for the smallest and sickest infants; for example, infants who need breathing support with a ventilator, weigh less than 1000 grams or were born before 28 weeks' gestation. NICUs can offer the entire range of neonatal care. Not all NICUs can provide highly specialised services, such as neonatal surgery and these services are concentrated at just a few hospitals. • **Local neonatal unit (LNU)** – These units still provide sophisticated care, but the infants are not as ill as those in the NICU. Infants weighing less than 1000 grams are sometimes cared for here if they are relatively strong. The local neonatal unit can provide continuous positive airways pressure (CPAP) for breathing support, and can look after infants who need their breathing to be stimulated. Infants can also receive intravenous (IV) or tube feeding in the local neonatal unit. • **Special care baby unit (SCBU)** – This level of care is sometimes referred to as 'low dependency'. The special care baby unit can offer infants some kinds of tube feeding, oxygen and phototherapy (light treatment) for jaundice. Special care is also for infants who need to have their breathing or heartbeat monitored. The unit can provide some intensive care in an emergency but not for longer periods. https://www.networks.nhs.uk/nhs-networks/yorkshire-humber-neonatal-families/useful-information/different-levels-of-care
NIDCAP	**The Newborn Individualized Developmental Care and Assessment Program (NIDCAP)** 'NIDCAP, originated in 1984 by Heidelise Als, PhD, is [a] comprehensive, family centered, evidence-based approach to developmental care for newborn and infant intensive care nurseries.' https://nidcap.org/
NNNS	**NICU Network Neurobehavioral Scale (NNNS)** 'Examines the neurobehavioural organization, neurological reflexes, motor development – active and passive tone, and signs of stress and withdrawal of the at-risk and drug-exposed infant. It was designed to provide a comprehensive assessment of both neurological integrity and behavioural function. Additionally, the NNNS documents the range of withdrawal and stress behavior likely to be observed in assessment and intervention with substance-exposed infants. This neurobehavioral assessment is applicable to term, normal healthy infants, preterm infants and infants at risk due to factors such as prenatal substance exposure.' https://www.brown.edu/research/projects/children-at-risk/about
NNU	**Neonatal unit** A term which may be used synonymously with neonatal intensive care unit, but is most commonly used to refer to level 2 units.

Non-pharmacological	A type of health intervention not based on medication/drugs.
Occupation	Occupation refers to practical and purposeful activities that allow people to live independently and have a sense of identity. This could be essential day-to-day tasks such as self-care, work or leisure. Infant 'occupations' are the activities that they engage in as they strive to master the skills they will need to adapt to their environment. These include participating in feeding, bathing, nurturing, play and learning, and early relationships.
Occupation-based assessment	Occupation-based assessment describes the consideration of an individual infant's early engagement patterns during routine caregiving and other elements associated with occupational performance. This includes identification of an infant's strengths and vulnerabilities as they experience and participate in caregiving interactions in the neonatal unit.
Occupational performance	The dynamic relationship between a person, a person's environment and their occupations.
Occupational therapist	An occupational therapist's role is to help people of all ages overcome the effects of disability caused by illness, ageing or accident so that they can carry out everyday tasks or occupations. An occupational therapist will consider all of the person's needs – physical, psychological, social and environmental. Occupational therapists work with many people, including children and young people, people with physical or learning disabilities, people with mental health issues, and older people. https://www.rcot.co.uk/about-occupational-therapy/what-is-occupational-therapy
p value	**Probability** 'The p value is a statistical measure that indicates whether or not an effect is statistically significant. For example, if a study comparing two treatments found that one seems more effective than the other, the p value is the *probability* of obtaining these results by chance. By convention, if the p value is below 0.05 (that is, there is less than a 5% probability that the results occurred by chance) it is considered that there probably is a real difference between treatments. If the p value is 0.001 or less (less than a 1% probability that the results occurred by chance), the result is seen as highly significant. However, a statistically significant difference is not necessarily clinically significant. 'If the p value shows that there is likely to be a difference between treatments, the *confidence interval* describes how big the difference in effect might be.' Glossary: http://www.nice.org.uk/website/glossary/glossary.jsp
Paediatric Intensive Care Unit	Hospital ward specialising in the care of critically ill infants and children.

Parent	Parent refers to the primary caregivers for the infant rather than the biological mother and father. For brevity in the document the word parent is used.
Parental attunement	See 'Attunement'.
Parenting occupations	See 'Co-occupations'.
Periventricular leukomalacia (PVL)	'Periventricular leukomalacia is a type of brain injury that is most common in babies born too soon (premature) or at low birthweight. The white matter (leuko) surrounding the ventricles of the brain (periventricular) is deprived of blood and oxygen leading to softening (malacia). The white matter is responsible for transmitting messages from nerve cells in the brain so damage to the white matter can cause problems with movement and other body functions.' https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/periventricular-leukomalacia/
Physiological regulation	Physiological (or autonomic) regulation refers to an individual's ability to regulate certain body processes such as rate of breathing, heart rate, digestion, temperature etc.
Positive touch	Positive touch is described as a specially adapted touch for infants who are premature or fragile and is given according to the individual behavioural and physiological responses of an infant (Warren and Bond 2010). It can include massage, gentle touch and supportive holding.
Postural support	Purposeful positioning of an infant with the goal of promoting self-regulation and facilitating an infant's participation in normal sensorimotor experiences, such as bringing their hand to their mouth and face (Vergara and Bigsby 2004).
Preterm infant	An infant born before 37 weeks' gestational age.
RCOT	**Royal College of Occupational Therapists** The Royal College of Occupational Therapists is a registered charity and wholly owned subsidiary of BAOT, which acts on behalf of all members of the Association. The College sets the professional and educational standards for the occupational therapy profession and represents the profession at the national and international levels. RCOT plays a crucial role in promoting the profession and meeting the professional needs of occupational therapy staff in the UK. https://www.rcot.co.uk/about-us/governance/how-we-are-run

RCOT SS – Children, Young People and Families	**Royal College of Occupational Therapists Specialist Section≈– Children, Young People and Families** RCOT SS – Children, Young People and Families is a branch of the College that that promotes high standards of professional practice within children's occupational therapy and, together with our members, continues to develop an evidence base for the profession. The Specialist Section represents occupational therapists working with children, young people and their families in a wide range of settings. https://www.rcot.co.uk/about-us/specialist-sections/children-young-people-and-families-rcot-ss
RCT	**Randomised controlled trial** 'A study in which a number of similar people are randomly assigned to two (or more) groups to test a specific drug, treatment or other intervention. One group (the experimental group) has the intervention being tested, the other (the comparison or control group) has an alternative intervention, a dummy intervention (placebo) or no intervention at all. The groups are followed up to see how effective the experimental treatment was. Outcomes are measured at specific times and any difference in response between the groups is assessed statistically. This method is also used to reduce bias.' Glossary: http://www.nice.org.uk/website/glossary/glossary.jsp
Respiratory compromise	A decline in respiratory function (i.e. the functions related to breathing) which may result in respiratory failure.
Self-efficacy	Parent self-efficacy refers to a parent's belief in their ability to perform their parenting role successfully (Wittkowski et al 2017).
Self-regulatory behaviours	'The active efforts on the part of the infant to regulate autonomic functions, motor control, and states of arousal, and availability for interactions with others, within the context of a dynamic environment' (Als 1982, referenced in Grenier et al 2003).
Sensory processing	'Sensory processing is a generic term used to describe the way in which sensation is detected, transduced and transmitted through the nervous system' (Roley et al 2007).
Septicaemia or sepsis	Also known as blood poisoning. A potentially life-threatening infection of the bloodstream.
SIGN	**Scottish Intercollegiate Guideline Network** SIGN develops evidence-based clinical practice guidelines for the National Health Service (NHS) in Scotland. http://www.sign.ac.uk
Torticollis	A dystonic condition defined by an abnormal head or neck position, which has a variety of causes.

Transitional care	Level of care provided to babies who may need support for feeding or medical matters that do not require admission to the neonatal unit. Transitional care units are usually located in maternity and mothers are not separated from their baby.
VLBW	**Very low birthweight** Birthweight of under 1.5kg (3 pounds 5 ounces) regardless of gestational age.
Washout period	The period during a clinical study when the participants do not receive any treatment that is under investigation.
White matter	'Nerve tissue of the central nervous system that is paler in colour than the associated grey matter because it contains more nerve fibres and thus larger amounts of the insulating material myelin.' (Martin 2003)

All websites in the glossary were accessed on 14.07.2022.

Appendix 2: Evidence tables

Each item of evidence used to support the recommendations has an associated evidence table.

The evidence tables are detailed in a separate document, *Occupational therapy in neonatal services and early intervention: practice guideline supplement – evidence tables*, which can be downloaded from the Royal College of Occupational Therapists' website at: https://www.rcot.co.uk/practice-resources/rcot-practice-guidelines

Appendix 3: Knowledge and skills frameworks

This section provides the knowledge and skills framework essential to occupational therapists working in neonatal and early intervention settings.

The British Association of Perinatal Medicine's service standards for hospitals providing neonatal care provides details about the neonatal occupational therapy specialist role (BAPM 2010, p14):

- Assessing the interaction of biological, developmental and psychosocial aspects of human function as expressed in daily activities and occupations.
- Administering complex standardised neurobehavioural assessments that provide information on the infant's neurobehavioural organisation, state control and self-regulatory behaviours.
- Using reliable non-invasive neurological assessments to identify early signs of neurological impairment.
- Identifying and advising on sensory issues affecting irritable babies and providing advice on developmentally supportive positioning to help prevent postural and developmental delays later in infancy.
- Helping to sensitise parents to their infant's behavioural cues, thereby enabling appropriate interactions and levels of stimulation, and providing developmental programmes as appropriate.
- Providing follow up after discharge, using evidence-based standardised developmental, cognitive and motor assessments.

The American Occupational Therapy Association's knowledge and skills for occupational therapy practice in the NICU (Vergara et al 2006, pp661–662):

- Medical knowledge base as a foundation for understanding infant behaviour.
- Factors that may influence infant and child development, including prenatal, perinatal and postnatal conditions and complications.
- Knowledge of the developmental course, abilities, and vulnerabilities of infants in the NICU (including neurobehavioural organisation, sensory development and processing of sensory information, motor function, and social-emotional development).
- Emerging competencies in infant occupation (including factors that influence participation in daily life activities, ability to cope with and participate in caregiving, engaging in nurturing interventions, and the inter-relationship between medical and developmental domains).

- Knowledge of evolving developmental approaches in the neonatal unit.
- Specific skills related to occupational therapy practice in the neonatal unit, including consultating/communicating with other professionals; safe and effective use of equipment; conducting appropriate assessments; assessing the effects of physical environment, caregiving practices, positioning, and nurturance on the infant's neurobehavioural organisation, sensory, motor, and medical status; and formulating an individualised therapeutic intervention plan that supports the infant's current level of function and facilitates optimal social-emotional, physical, cognitive, and sensory development of the infant within the context of the family and the NICU.
- Work from a family-centred perspective through acknowledgement of the family as a basis for collaboration, recognising adult learning styles, supporting parent–infant interactions, and supporting the transition of the infant and family from hospital to home.

Appendix 4: Examples of occupational therapy services in neonatal settings

Occupational therapy services provided in neonatal settings across the UK differ in structure, scope and resourcing.

The information included in this appendix aims to provide information and examples of current services that may be useful when considering the development of neonatal services. More information on recommended occupational therapy staffing provision can be found in the document *Occupational therapy staffing on neonatal units* (RCOT 2018).

Identification of high-risk infants who may benefit from occupational therapy services can be supported by the implementation of a framework that combines infant biological-biomedical and psychosocial-physical environment risk criteria to identify those infants who are at risk for poor developmental outcomes (Laadt et al 2007). Laadt et al (2007) developed a System of Risk Triage (SORT) that assists therapists to identify each infant's risk for subsequent developmental problems, and identify those who would benefit from referral for early intervention services.

The SORT framework has been modified with permission to reflect the provision of neonatal services in the UK.

Framework to guide referral and developmental intervention decisions in the neonatal unit

Table A4.1: Infant biomedical axis for triage tool

Infant biomedical axis	**A Low biomedical risk**	Inpatient: any infant who is separated from his mother due to medical needs. Outpatient: any infant not in another risk category whose parents have concerns about their development.
	B Moderate biomedical risk	Moderate risk of developmental delay or disability, e.g. due to birthweight 1000–1250g; gestational age 28–32 weeks; IUGR >34 weeks; >week hospitalised for stabilisation.
	C High biomedical risk	High risk of developmental delay/disability, e.g. due to birthweight <1000; gestational age <29 weeks; surgery with prolonged hospitalisation; low Apgar score at 10 mins; identified CNS injury (e.g. HIE, seizures, meningitis, IVH Grade IV; bilateral PVL); abnormal tone or movements; delayed/disorganised feeding; ventilation >10 days; moderate sensory loss.
	D Established biomedical risk	Infants with conditions that are associated with disability, e.g. syndromes and congenital disorders such as Down Syndrome, foetal alcohol syndrome; significant neurological findings on US or MRI and signs of abnormal movements, persistent irritability, dysfunctional feeding; congenital malformations affecting development; severe sensory loss; palliative care.

Table A4.2: Psychosocial environment axis for triage tool

Psychosocial environment axis		
1 – Adequate environment	**2 – Moderate risk environment**	**3 – Established risk**
Family with adequate psychosocial, physical and material resources to support their infant's growth, developmental progress and general wellbeing.	Family in need of help to identify resources to support infant growth, development and wellbeing, e.g. due to other demands, lack of engagement with community, substance abuse, poverty, history of psychiatric problems or learning disability, life-threatening conditions etc. Lack of family support.	Psychosocial environmental circumstances are precarious and infant's future safety is in question, e.g. history of violence in the home, no prenatal care, history of other children removed from home; criminal record; involvement with child protection; maternal isolation; homelessness; refugee status; substance abuse.

Table A4.3: Decision-making framework

		Psychosocial environment axis		
		1. Adequate environment	**2. Moderate risk environment**	**3. High-risk environment**
Infant biomedical axis	**A Low risk**	Advocates for and promotes appropriate developmental environment for all infants and families in the NNU, e.g. light, sound, seating for skin-to-skin, parent and infant participation in co-occupations*** etc.	Facilitation of parent–infant co-occupations***; guidance to promote attunement, awareness of behavioural regulation and self-confidence.	Assessment of parenting efficacy.
	B Moderate risk	Specific environmental adaptations appropriate for age and stage of development to support all domains,* e.g. optimal positioning for autonomic regulation, head shape, motor organisation; to facilitate behavioural organisation. Support parental role, e.g. parent-focused interventions with maternal sensitivity elements (e.g. reading and responding to infant cues) to reduce psychosocial impact. Pre-discharge neurobehavioural/neurodevelopmental assessment and anticipatory guidance.	**As for 2A and 1B plus:** Individual guidance re: parenting occupations using adapted techniques to match infant's sensitivity and to facilitate behavioural organisation. Monitor parental/family organisation/ vulnerability and recommend support/ coping strategies.	**As for 3A and 2B plus:** Contributes to multidisciplinary/multi agency developmental plan with safeguarding in mind.
	C High risk	**As for 1B plus:** Individualised developmentally supportive care plans** a) to protect infant from secondary 'disabilities', e.g. postural, feeding; b) to promote behavioural competence in all domains; c) to reduce stress/pain; d) to support parenting role. Developmental surveillance and therapeutic interventions at home with emphasis on occupational competence (based on cognitive/executive functions, social, behavioural, sensory processing and functional motor skills).	**As for 2B and 1C plus:** Build strong relationship with family and support them to engage with services, e.g. follow-up clinics, community services, and to make the transition to child development services as needed.	**As for 3B plus:** Individualised developmentally supportive care plans on NNU and developmental plan to facilitate transition to ongoing carer arrangements and services post-discharge.
	D Established condition	Therapeutic interventions to promote development and prevent disability (e.g. contractures), e.g. positioning, handling and movement; sensory; splinting. Incorporates strategies and family education into daily care activities (occupations). Discharge planning. Liaison with community resources.	**As for 1D and 2C**	**As for 1D and 3C**
	All groups	Active role in managing a developmentally appropriate sensory and social environment for infant and family-centred care. Guidance about appropriate educational materials for staff and parents. Promote assessment of neonatal pain and identification of appropriate pain management strategies.		
	Notes	*Behavioural domains are autonomic, motor, states of arousal, attention and self-regulation. **Developmentally supportive care plans include recommendations for promoting autonomic stability (including digestion and energy conservation), positioning comfort and efficacy, pain management, protection of sleep, social interaction, sensory processing and feeding readiness. ***Co-occupations are caregiving activities in which parents and infants actively engage that address infant needs but also support the developing parent–infant relationship (including positive touch, nurturing, feeding, bathing, early reciprocal interaction etc.)		

Adapted with kind permission from Virginia Laadt, PhD, OTR/L from Laadt et al 2007.

Examples of neonatal service delivery

Neonatal occupational therapy services differ across the UK. Below are five models being used currently that include designated posts, joint posts with paediatrics or in-reach from community services. There are a number of similarities with all posts; the most common are:

- Contributes to developmental care policies, guidelines and projects.
- A resource for nursing, medical and therapy team in terms of preterm infant development and environmental modification.

Table A4.4: Summary of unit and occupational therapists' band/time

Unit details	Occupational therapy banding and time
Joint neonatal and acute paediatric post (London) Two neonatal units (Level III and Level II) in two locations, approximately 42 beds.	0.6 WTE Band 8a clinical specialist neonates 0.2 WTE Band 7 clinical specialist neonates
Neonatal post (London) Level II unit with 30 beds – 4 ICU, 6 HDU, 10 SCBU and 10 individualised care rooms where families stay with their baby from admission to discharge.	0.4 WTE 15 hours per week of Band 8a clinical specialist Neonates only
Joint neonatal and community paediatric post (Scotland) Level III unit serving north and south of the county with 8 ICU, 4 HDU cots and 16 special care cots and transitional care. Community time allows follow up of babies at home and flexibility to transfer to occupational therapists colleagues in community team.	0.6 WTE Band 7 advanced practitioner 0.3 WTE on neonatal unit and in outpatient clinics 0.3 WTE days community follow up
Community occupational therapist with neonatal/developmental follow-up speciality (rural Scotland setting) Level II neonatal unit with 12 beds for babies over 30 weeks' GA. Those babies born extremely preterm or requiring surgery are repatriated after their stay on a Level III unit. Provide a region-wide joint therapy follow-up service with outpatient clinics held at two sites. Community caseload service is offered to families as appropriate.	Band 7 clinical specialist 1–1.53 days per month on developmental screening 2–3 days per month on assessment and treatment of infants identified as requiring this 1 day per month (averaged) in supporting neonatal unit round, including planned project work, training (shared among therapy team) Band 6 paediatric occupational therapist 12 days per month on developmental screening 1 day per month on assessment and treatment of infants identified as requiring this

Table A4.5: Summary of occupational therapists' roles

Post	Role on neonatal unit	Role in follow up	Benefits of structure
Joint neonatal and acute paediatric post (London)	Blanket referral system used, based on medical and psychosocial need. Individualised assessments and interventions for infants from admission to discharge across both intensive care and special care. Attends multidisciplinary ward rounds dependent on capacity.	Babies with identified developmental needs or expected neurological sequelae are referred to their local child development service before discharge. Twenty-four-month corrected developmental assessments (Bayley III). Participate in Next Steps baby group. Runs as an eight-week programme all year. Ad hoc appointments as needed for specific occupational therapy input in particular if concerns about neurological sequelae noted and neonatologist unsure whether the baby requires full referral to community. Neurological assessments for babies with brain malformations identified as part of the foetal medicine clinic jointly with physiotherapy or with neurologist.	Facilitates transfer from neonatal unit to paediatrics when necessary for ongoing care. Familiar face on paediatrics who knows the baby's story if admitted after discharge from the neonatal unit. Resource for paediatrics in terms of specialist assessment of preterm infants and neonates. Training and education for therapists, nurses and doctors on working with small babies and their families on paediatrics. Opportunities to up-skill paediatric occupational therapists as succession planning.

Post	Role on neonatal unit	Role in follow up	Benefits of structure
Neonatal post (London)	Blanket referral system used, based on medical and psychosocial need. Individualised assessments and interventions for infants from admission to discharge across both intensive care and special care. Attends multidisciplinary ward rounds. Responsible for the organisation and delivery of 'Little Stars', a five-week follow-up group, offered to all families following an NICU admission. Responsible for the organisation and delivery of 'Supper Club', an evening group for all family members to provide support and developmental advice. Responsible for the rolling education programme that runs for all families as part of the parents' support group. Responsible for parent newsletter. Co-opted member of network board, feeding data directly back to board level, provides information on role of occupational therapy for network website.	All infants born less than 30 weeks or who have had an MRI will be offered neurodevelopmental follow up. Newborn Behavioural Assessment Scale (NBAS) and Prechtl, neurological assessment of general movement provided at term. Bayley III provided at 3 months' corrected with Prechtl. Bayley III provided at 6 months, 1 year and 2 years. Ad hoc appointments as needed for specific occupational therapy input.	Integrated model of practice, where occupational therapist is a core member of the neonatal team. Proactive model not waiting for problems to occur, but providing developmentally supportive advice from the outset. Familiar face in follow up who knows the baby's story. Resource for paediatrics in terms of specialist assessment of preterm infants and neonates. Training and education for therapists, nurses and doctors on working with all babies and their families in neonatal care.

Post	Role on neonatal unit	Role in follow up	Benefits of structure
Joint neonatal and community paediatric post (Scotland)	Criteria for therapy follow up – babies born before 30 weeks' GA, IVH grade III or IV, HIE and any baby at the discretion of the consultant. Individualised assessments and interventions for infants from admission to discharge across intensive care and special care. Meet with parents to explain therapy role and follow up, in conjunction with discharge liaison midwife in the Neonatal unit.	Neonatal care pathway for therapy provision for babies preterm and HIE until 24 months' corrected age. Babies with identified developmental needs or expected neurological sequelae can be followed up in the community by the Band 7 advanced practitioner or transferred to paediatric occupational therapy colleagues. Neurodevelopment clinics twice a month with consultant neonatologist, occupational therapist, physiotherapist and/or speech and language therapist. Babies assessed using Bayley III at 6, 12 and 18 or 24 months' corrected age.	Resource for specialist assessment of preterm infants and neonates to provide early therapy intervention. Facilitates transfer from neonatal unit to therapy outpatient clinics and if required to community caseload with continuity of therapist. Training and education for therapists, nurses and doctors on working with small babies and their families. Opportunities to facilitate training of paediatric occupational therapists as succession planning.

Post	Role on neonatal unit	Role in follow up	Benefits of structure
Community occupational therapy with neonatal/ developmental follow-up speciality (rural) in South West Scotland	Attendance at the weekly medical unit round is shared between the Joint Therapy Baby Service team members (occupational therapist (OT), physiotherapist (PT), and speech and language therapist (SLT)). Referrals are identified and made as per the pre-set criteria (in line with national guidelines) to feed into the therapy follow-up service. Informal advice provided by occupational therapist, physiotherapist and/or speech and language therapist as required during inpatient period within the unit round capacity. Attends multidisciplinary unit rounds.	Joint service provision from OT, PT, SLT with links to wider MDT including health visiting and consultant paediatricians. Referrals are fed into either the Baby Clinic (preventative screening) care pathway or Baby Caseload care pathway should any additional concerns or indicators be present. Infants born before 29 GA are seen for follow up until 24 months' corrected age and infants between 29 and 32 GA until 18 months' corrected age. Planned reviews at post-discharge, 4 months, 8 months, 12 months, 18 months (and 24 months as above) corrected ages for informal and formal assessment including use of developmental assessments, e.g. Bayley III. Additional review appointments can be made depending on need. Clients can transfer between clinic and caseload care pathways as required.	Facilitate transfer from neonatal unit to therapy follow up/caseloads when necessary for ongoing care. Resource for transdisciplinary team in terms of developmental care and later occupational outcomes. Training and education for therapists, nurses and doctors on working with small babies and their families on paediatrics. Opportunities to up-skill paediatric occupational therapist as succession planning.

Appendix 5: Guideline Development and Review groups

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Appendix 6: Conflicts of interest declarations

Declarations were made in line with the conflicts of interest procedures (RCOT 2020, Section 9.6) as follows:

- Guideline group members, co-opted critical appraisers and occupational therapists involved in the consultation activity identified their membership of one or more professional organisations or specialist neonatal-related forums, which included the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families, Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and National Association of Neonatal Therapists (NANT).

- One member of the Guideline Development Group (first edition) and Guideline Review Group (second edition) was a co-author of evidence included within the guideline. Careful allocation of critical appraisal, and the consensus approach taken in the guideline development meetings, meant there was no undue bias from any authorship.

- Two members of the Guideline Development Group (first edition) were involved in the development of European standards for developmental care. Another Guideline Development Group member (first edition) was a member of the NICE guideline group for developmental follow up of preterm infants.

- Three group members in the first edition and two members in the second edition are involved in the Brazelton Centre UK, four members from the first and second editions are involved in NIDCAP, four first and second edition members are FINE trainers via Bliss and one first edition member was involved with the Bobath Centre.

- One co-opted appraiser for the first edition was the chair of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families – Neonatal Forum.

- The co-Editorial Lead for both editions was an officer of the Royal College of Occupational Therapists.

- Stakeholder and peer reviewer declarations included interests related to neonatal organisations, services and research/publications.

The nature of declarations made by all those involved in the guideline development was related to professional interests and expertise in clinical practice, education or research.

There were no conflicts of interest declared by parents involved in the consultation, other than personal experience of a neonatal and/or early intervention occupational therapy service.

No commercial or financial interests were declared.

The adherence to the Royal College of Occupational Therapists' conflicts of interest policy, the nature and management of the above declarations, together with the robust guideline development methodology, mean that the potential for any bias has been taken into account and mitigated.

Appendix 7: Literature search strategy – first edition

Table A7.1: Search terms and strings

String 1 – Pure neonate terms	String 2 – Paediatric terms	String 3 – Population and settings-related terms	String 4 – Interventions	String 5 – Related interventions	String 6 – Occupational therapy	String 7 – Occupational therapy related terms	String 8 – Finance and value terms	String 9 – Setting terms
Neonat* OR Preterm OR Premature OR Preemie* OR Low birthweight	Paediatric OR Pediatric OR Newborn* OR Infant OR Baby OR Babies	Matern*	Assessment* OR Screen* OR Identif* OR Developmentally supportive care OR Positioning OR Pain management OR Massage OR Feeding OR Co-occupant* OR Sensor* OR Cognit* OR State regulat* OR Neurobehav* OR Parent OR Parents OR Parenthood OR Parenting OR Stress OR Stressful OR Stressed OR Environment* OR Neurodevelopment* OR Neuro-development* OR	Developmental care OR Skin-to-skin OR Kangaroo care OR Couplet care OR NIDCAP OR Individualised developmental care OR Developmentally supportive care OR Positioning OR Pain management OR Massage OR Feeding OR Co-occupat* OR Sensor* OR Cognit* OR State regulat* OR Neurobehav* OR Parent OR Stress management OR Environment OR	Occupational therap*	Occupation* OR Rehabilit* OR Enable* OR Enabling OR Enabled OR Multidisc* OR Activit* OR Self care OR Self-care OR Participat* OR Engage OR Engaged OR Engaging OR Engagement OR Therapy OR Therapies	Econom* OR Cost* OR Financ* OR Saving* OR Afford OR Affordable OR Expens* OR Inexpens* Loss making OR Loss-making OR Expenditure* OR Fiscal OR Fund* OR Value n2 for OR Cost effective* OR Cost-effective* OR Cost benefit* OR Cost-benefit* Cost-control OR Benefit-cost* OR Health care cost* OR	NICU OR Neonatal intensive care OR SCBU OR Special care baby unit OR NIC OR PICU* OR Critical care OR Paediatric Intensive care OR Neonatal unit OR Local neonatal unit OR LNU OR Paediatric intensive care unit OR Neonatal environment OR

String 1 – Pure neonate terms	String 2 – Paediatric terms	String 3 – Population and settings-related terms	String 4 – Interventions	String 5 – Related interventions	String 6 – Occupational therapy	String 7 – Occupational therapy related terms	String 8 – Finance and value terms	String 9 – Setting terms
			Neuro development* OR Developmental outcome* OR Early intervention* OR Ultra-early intervention* OR Ultra early intervention* OR Transitional care OR Family* OR Families OR Familial OR Parent engagement OR Attachment OR Attunement	Neurodevelopment OR Developmental outcomes OR Early intervention OR Ultra-early intervention OR Transitional care OR Family centred OR Parent engagement OR Family integration OR Family intervention OR Attachment OR Attunement OR General movements			Hospital cost* OR Health expenditure* OR Capital expenditure* OR Health economic* OR Fiscal OR Financial OR Finance OR Deductible* OR Coinsurance OR Coinsured OR Fee OR Fees OR Charge* OR Budget* OR Socioeconomic OR Insurance OR Insure OR Insured	Transitional care unit OR Maternity unit OR Hospital clinic OR Early-years service* OR Early intervention service OR Private clinic* OR Education provider* OR Child care setting OR Nursery school OR Child* ward

Core databases or platforms

A title/abstract/descriptor search was undertaken for the various search string combinations.

Key:

ab = abstract de = descriptors hw = heading words id = key words
kw = keyword oh = outline heading sh = subject heading su = subject
ti = title

Table A7.2: Core databases or platforms: occupational therapy-specific search

Database or platform and search date	EBSCO*	Ovid*
	13.01.2016 and 26.01.2016	13.01.2016, 15.01.2016 and 26.01.2016
Search term strings (below) and fields searched (right)	ti, ab, su	ab, de, hw, id, oh, sh, ti
Strings: 1 AND 6	257	66
Strings: 1 AND 3 AND 6	15	3
Strings: 1 AND 4 AND 6	136	50
Strings: 1 AND 6 AND 7	169	66
Strings: 1 AND 6 AND 8	40	2
Strings: 1 AND 6 AND 9		34
Strings: 1 AND 3 AND 4 AND 6	12	2
Strings: 1 AND 3 AND 6 AND 7	15	3
Strings: 1 AND 3 AND 6 AND 9		1
Strings: 1 AND 6 AND 8 AND 9		1
Strings: 2 AND 6 AND 9	215	26
Strings: 2 AND 3 AND 6 AND 9	4	1
Strings: 2 AND 4 AND 6 AND 9	119	24
Strings: 2 AND 6 AND 8 AND 9	35	1
Strings: 2 AND 6 AND 7 AND 9*	145	26
Strings: 2 AND 3 AND 6 AND 7 AND 9*	4	1
Strings: 2 AND 3 AND 4 AND 6 AND 9	2	1
Strings: 3 AND 4 AND 6	74	25

Database or platform and search date	EBSCO*	Ovid*
	13.01.2016 and 26.01.2016	13.01.2016, 15.01.2016 and 26.01.2016
Strings: 3 AND 6 AND 7 AND 9	4	1
Total results	1,246	334
Removed via platform de-duping and/or filter options (date/language)	*856*	*145*
Total for cleansing	390	189

Medline, CINAHL – accessed via EBSCOHOST platform
AMED, HMIC, PsycINFO, Social Policy and Practice – accessed via Ovid platform
*EBSCOHOST consisted of two searches and Ovid consisted of three searches, with details available upon request.

Table A7.3: Core databases or platforms: intervention-specific search

Database or platform and search date	EBSCO*	Ovid
	25.02.2016 and 18.03.2016	25.02.2016
Search term strings (below) and fields searched (right)	ti, su	ti
Strings: 1 AND 5 AND 9	1,008	256
Strings: 2 AND 5 AND 9	1,112	331
Total results	2,120	587
Removed via platform de-duping and/or filter options (date/language)	*0*	*176*
Total for cleansing	2,120	411

*EBSCO consisted of two searches, with details available upon request.

Table A7.4: Specialist databases or platforms – occupational therapy specific

Database or platform	Fields	Terms	Number retrieved	Date of search
OT Search	ti OR su	String 1 OR String 2	**185**	29/01/16
Cochrane	ti OR ab OR kw	String 2 AND (String 9 OR String 1) AND String 6	**68**	04/02/16
OTSeeker	ti	String 1 OR NICU OR SCBU OR Special care baby unit* OR PICU Newborn* OR infant* OR Baby or Babies OR toddler* OR pre-school OR preschool OR 'early childhood' NICU OR Neonatal intensive care OR SCBU OR Special care baby unit OR NIC OR PICU* OR Paediatric intensive care OR Pediatric intensive care OR Neonatal unit OR Transitional care unit OR Maternity unit OR Early-years service* OR Early intervention service OR Education provider* OR Child care setting OR Nursery school OR Child* ward	**264**	04/02/16
OTDBASE	ab	Neonate OR Neonates OR Neonatal Newborn OR Newborns OR Low birthweight	**41**	19/01/16
Handsearch	N/A	N/A	**2**	Various

No searches were carried out in these specialist databases for intervention-specific literature.

Appendix 8: Literature search strategy – second edition

Table A8.1 Monitoring search and full review search terms and strings

String 1 – Pure neonate terms	String 2 – Pediatric terms	String 3 – Population and settings related terms	String 4 – Interventions	String 5 – Related interventions	String 6 – Occupational therapy	String 7 – Occupational therapy related terms	String 8 – Finance and value terms	String 9 – Setting terms
Neonat* OR Preterm OR Premature OR Preemie* OR Low Birthweight	Paediatric* OR Pediatric* OR Newborn* OR Infant* OR Baby OR Babies	Matern*	Assessment* OR Screen* OR Identif* OR Developmentally supportive care OR Positioning OR Pain management OR Massage OR Feeding OR Co-occupat* OR Sensor* OR Cognit* OR State regulat* OR Neurobehav*	"Developmental care" OR "Skin-to-skin" OR "skin-to-skin" OR "Kangaroo care" OR "Couplet care" OR NIDCAP OR "Individualised developmental care" OR "Developmentally supportive care" OR Positioning OR Pain management	Occupational therap*	Occupation* OR Rehabilit* OR Enable* OR Enabling OR Enabled OR Multidisc* OR Multi-disc* OR Activit* OR Self care OR Self-care OR Participat* OR Engage OR Engaged Or Engaging OR	Econom* OR Cost* OR Financ* OR Saving* OR Afford OR Affordable OR Expens* OR Inexpens* OR Loss making OR Loss-making OR Expenditure* OR Fiscal OR Fund* OR	NICU OR Neonatal intensive care OR SCBU OR Special care baby unit OR NIC OR PICU* OR Critical care OR Paediatric intensive care OR Intensive care OR Neonatal unit OR Local neonatal unit OR LNU OR

String 1 – Pure neonate terms	String 2 – Pediatric terms	String 3 – Population and settings related terms	String 4 – Interventions	String 5 – Related interventions	String 6 – Occupational therapy	String 7 – Occupational therapy related terms	String 8 – Finance and value terms	String 9 – Setting terms
			OR Parent OR Parents OR Parenthood OR Parenting OR Stress OR Stressful OR Stressed OR Environment* OR Neurodevelopment* OR Neuro-development* OR Neuro development* OR Developmental outcome* OR Early intervention* OR Ultra-early intervention* OR Ultra early intervention* OR Transitional care OR Family*	OR Massage OR Feeding OR Co-occupat* OR Sensor* OR Cognit* OR “State regulat*” OR Neurobehav* OR Parent OR “Stress management” OR Environment OR Neurodevelopment OR “Developmental outcomes” OR “Early intervention” OR “Ultra-early intervention” OR “Transitional care”		Engagement OR Therapy OR Therapies	(Value n2 for) OR Cost effective* OR Cost-effective* OR Cost benefit* OR Cost-benefit* OR Cost-control OR Benefit-cost* OR Health care cost* OR Hospital cost* OR Health expenditure* OR Capital expenditure* OR Health economic* OR Fiscal OR Financial OR Finance OR Deductible* OR Coinsurance	Paediatric intensive care unit OR Neonatal environment OR Transitional care unit OR Maternity unit OR Hospital clinic OR Early-years service* OR Early intervention service OR Private clinic* OR Education provider* OR Child care setting OR Nursery school OR Child* ward

String 1 – Pure neonate terms	String 2 – Pediatric terms	String 3 – Population and settings related terms	String 4 – Interventions	String 5 – Related interventions	String 6 – Occupational therapy	String 7 – Occupational therapy related terms	String 8 – Finance and value terms	String 9 – Setting terms
			OR Families OR Familial OR Parent engagement OR Attachment OR Attunement	OR “Family centred” OR “Parent engagement” OR “Family integration” OR “Family intervention” OR Attachment OR Attunement OR “General movements”			OR Coinsured OR Fee OR Fees OR Charge* OR Budget* OR Socioeconomic OR Insurance OR Insure OR Insured	

Monitoring search strategy

Monitoring searches were carried out in 2018 and 2019, and replicated the first edition guideline search terms and strings for occupational therapy-specific literature. However, monitoring searches only utilised the EBSCO (Medline, CINAHL) and Ovid (AMED, HMIC, PsycINFO, Social Policy and Practice) platforms.

Table A8.2 Monitoring review platforms and search terms

Database or platform and search date	EBSCO		Ovid	
	08.10.18	24.09.19	08.10.18	26.09.19
Search term strings (below) and fields searched (right)	Ti, ab, de		Ti, ab, de, hw, sh, id	
Strings: 1 AND 6	6	64	7	4
Strings: 1 AND 3 AND 6	4	7	1	0
Strings: 1 AND 4 AND 6	48	39	7	4
Strings: 1 AND 6 AND 7	60	63	7	4
Strings: 1 AND 6 AND 8	10	5	0	1
Strings: 1 AND 6 AND 9	28	24	3	2
Strings: 1 AND 3 AND 4 AND 6	3	5	1	0
Strings: 1 AND 3 AND 6 AND 7	4	7	1	0
Strings: 1 AND 3 AND 6 AND 9	1	2	0	0
Strings: 1 AND 6 AND 8 AND 9	4	2	0	0
Strings: 2 AND 6 AND 9	49	38	5	3
Strings: 2 AND 3 AND 6 AND 9	2	2	0	0
Strings: 2 AND 4 AND 6 AND 9	42	33	5	3
Strings: 2 AND 6 AND 8 AND 9	13	8	1	0
Strings: 2 AND 6 AND 7 AND 9	49	38	5	3
Strings: 2 AND 3 AND 6 AND 7 AND 9	2	2	0	0
Strings: 2 AND 3 AND 4 AND 6 AND 9	2	2	0	0
Strings: 3 AND 4 AND 6	17	17	1	0
Strings: 3 AND 6 AND 7 AND 9	2	2	0	0
Total results	346	360	44	24
Removed via platform de-duping and/or filter options (date/language)	259	273	35	19
Total for cleansing	**87**	**87**	**9**	**5**

Full review search: Core databases or platforms

In the full review search, Ovid and Ebsco platforms terms were searched in the title, abstract and descriptor field, unless where noted. For Ovid, this included the ID field.

Key:

ab = abstract
de = descriptors
hw = heading words
id = key words
kw = keyword
oh = outline heading
sh = subject heading
su = subject
ti = title

Table A8.3: Full review core databases or platforms: occupational therapy-specific search

Database or platform and search date	EBSCO	Ovid
	06.11.20	06.11.20
Search term strings (below) and fields searched (right)	Ti, ab, de	Ti, ab, de, hw, sh, id
Strings: 1 AND 6	141	16
Strings: 1 AND 3 AND 6	8	1
Strings: 1 AND 4 AND 6	114	15
Strings: 1 AND 6 AND 7	141	16
Strings: 1 AND 6 AND 8	17	1
Strings: 1 AND 6 AND 9	70	10
Strings: 1 AND 3 AND 4 AND 6	8	1
Strings: 1 AND 3 AND 6 AND 7	8	1
Strings: 1 AND 3 AND 6 AND 9	3	0
Strings: 1 AND 6 AND 8 AND 9	9	0
Strings: 2 AND 6 AND 9	134	13
Strings: 2 AND 3 AND 6 AND 9	6	0
Strings: 2 AND 4 AND 6 AND 9	120	12
Strings: 2 AND 6 AND 8 AND 9	34	1
Strings: 2 AND 6 AND 7 AND 9	134	13
Strings: 2 AND 3 AND 6 AND 7 AND 9	6	0
Strings: 2 AND 3 AND 4 AND 6 AND 9	6	0
Strings: 3 AND 4 AND 6	51	2

Database or platform and search date	EBSCO	Ovid
	06.11.20	06.11.20
Strings: 3 AND 6 AND 7 AND 9	6	0
Total results	1,016	102
Removed via platform de-duping and/or filter options (date/ language)	*804*	*81*
Total for cleansing	212	21

Medline, CINAHL – accessed via EBSCOHOST platform
AMED, HMIC, APA PsycINFO, Social Policy and Practice – accessed via Ovid platform

Table A8.4: Full review core databases or platforms: intervention-specific search

Database or platform and search date	EBSCO*	Ovid
	05.11.20	05.11.20
Search term strings (below) and fields searched (right)	ti, su	ti
Strings: 1 AND 5 AND 9	1,229	92
Strings: 2 AND 5 AND 9	1,306	84
Total results	2,535	176
Removed via platform de-duping and/or filter options (date/ language)	*1,204*	*65*
Total for cleansing	1,334	111

Table A8.5: Full review specialist databases or platforms – occupational therapy specific

Database or platform	Fields	Terms	Number retrieved	Date of search
OT Search	ti OR su	String 1 OR String 2	**62**	05.11.20
Cochrane	ti OR ab OR kw	String 6 AND ((String 2 AND String 9) OR String 1)	**128**	05.11.20
OTSeeker	ti or ab	String 1 OR NICU OR SCBU OR Special care baby unit* OR PICU OR Newborn* OR infant* OR Baby or Babies OR toddler* OR pre-school OR preschool OR 'early childhood' OR NICU OR Neonatal intensive care OR SCBU OR Special care baby unit OR NIC OR PICU* OR Paediatric intensive care OR Pediatric intensive care OR Neonatal unit OR Transitional care unit OR Maternity unit OR Early-years service* OR Early intervention service OR Education provider* OR Child care setting OR Nursery school OR Child* ward	**5**	06.11.20
OTDBASE	ab	Neonate OR Neonates OR Neonatal OR Newborn OR Newborns OR Low birthweight OR Preterm OR Premature OR Preemie OR Preemies OR NICU OR SCBU OR PICU	**0**	05.11.20

No searches were carried out in these specialist databases for intervention-specific literature.

Appendix 9: Acknowledgements

The Guideline Development Group would like to thank all those who have contributed to the development of this practice guideline.

A9.1 Guideline development – first edition

A9.1.1 Parent consultees

- The five parents who attended a group discussion at the Royal Free NHS Trust.
- Mrs Sarah Fulton.

A9.1.2 Stakeholders

Seventeen organisations or individuals commented on the draft guideline consultation. The following wished to be acknowledged in the guideline:

- Bliss
- Hilary Cruikshank, Clinical Specialist Neonatal Physiotherapist, NHS Lothian/Chair Association of Paediatric Chartered Physiotherapists
- Linda Hunn, Associate Director/Lead Nurse, Trent Perinatal and Central Newborn Networks
- Dr Helen Mactier, Consultant Neonatologist, British Association of Perinatal Medicine Honorary Secretary
- Ruth Moore, Manager/Lead Nurse, Staffordshire, Shropshire and Black Country Newborn and Maternity Network
- Northwest Neonatal Operational Delivery Network
- Julia Petty, Senior Lecturer in Children's Nursing, University of Hertfordshire/Neonatal Nurses Association Executive Member
- Royal College of Midwives
- Royal College of Paediatrics and Child Health, on behalf of five members
- Julie Taylor, Clinical Governance Lead for Paediatrics and Neonates, Dudley Group NHS Foundation Trust – Russells Hall Hospital

The following organisations commented on the guideline scope: Neonatal Nurses Association UK; Royal College of Speech and Language Therapists (Neonatal Special Interest Group); Bliss; Association of Paediatric Chartered Physiotherapists (Neonatal).

A9.1.3 External peer reviewers

Two independent reviewers appraised the draft guideline:

- Dr Roberta Pineda, PhD OTR/L, Assistant Professor, Washington University School of Medicine/Co-Chair Neonatal Therapy National Certification Board.
- Dr Anne Gordon, Senior Consultant Occupational Therapist, Evelina London Children's Hospital, Guy's and St Thomas' Hospital NHS Foundation Trust/Visiting Senior Lecturer, Institute of Psychiatry, Psychology and Neuroscience, King's College London

A9.1.4 Co-opted critical appraisers

- Dr Maria Giatsi Clausen, PhD in Occupational Therapy, Lecturer in Occupational Therapy, Division of Occupational Therapy and Art Therapies, School of Health Sciences, Queen Margaret University, Edinburgh
- Laura Perez-Adamson, Post-Graduate Diploma OT, Clinical Lead Occupational Therapists NICU and SCBU and Team Leader for the Early Years' Development Team, Whittington Health NHS Trust, Member of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families and Chair of Clinical Forum: Neonatal
- Kelly Fielden, Master of Occupational Therapy, BA App Sc, Lecturer in Occupational Therapy, Department of Health, Psychology and Social Studies, University of Cumbria, Member of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families

A9.1.5 Occupational therapists

Seven occupational therapists responded to the draft guideline consultation and the following wished to be acknowledged in the guideline:

- Kelly Fielden, Lecturer in Occupational Therapy, University of Cumbria
- Dr Susan Mitchell, Lecturer in Occupational Therapy, University of Plymouth, and private practitioner
- Sophie Olley, Clinical Specialist Occupational Therapist, Cardiff and Vale University Health Board – Children's Hospital for Wales
- Anne Taplin, Lead Occupational Therapist – Children and Young People, Cardiff and Vale University Health Board – Children's Hospital for Wales

A9.2 Guideline development – second edition

A9.2.1 Parent consultees

We are grateful to the 27 parents who responded to the online survey.

A9.2.2 Stakeholders

Nine stakeholders responded to the draft guideline consultation and the following consented to be acknowledged in the guideline:

- Josie Anderson, Policy Research and Campaigns Manager, Bliss

- Kelly Harvey, Lead Nurse, North West Neonatal Operational Delivery Network and Neonatal Nurses Association
- Ailie Hodgson, Neonatal Network Care Coordinator
- Karen Mainwaring, Senior Lead Nurse, North West Neonatal Operational Delivery Network and Neonatal Nurses Association
- Sarah Neilson, Clinical Specialist Occupational, Therapist Evelina London Children's Hospital; and Lead, London Neonatal Network Occupational Therapy

A9.2.3 External peer reviewers

Two independent reviewers appraised the draft guideline:

- Jenene Craig, PhD, MBA, OTR/L, CNT, Neonatal Occupational Therapist and Professor and Program Manager, Fielding Graduate University
- Gail A. Poskey, PhD, OTR, CNT, Associate Professor, School of Occupational Therapy, Texas Women's University

A9.2.4 Co-opted critical appraisers

We are grateful to two co-opted critical appraisers who assisted with the appraisal process. One consented to be recognised in the guideline:

- Jennifer Dean, Masters Occupational Therapy, Specialist Children's Occupational Therapist, Imperial College Healthcare NHS Trust, London

A9.2.5 Occupational therapists

We are grateful to the occupational therapists who responded to the draft guideline consultation.

The Guideline Development Group would additionally like to thank the following:

- The Royal College of Occupational Therapists' Library Service
- The Royal College of Occupational Therapists' Publications Group and supporting Officers Julia Roberts, Quality Programme Manager; Tessa Fincham, Publications Manager; and Julia Roscoe, Research and Development Assistant.

Appendix 10: Parent consultation questionnaire – second edition

Introduction

We, the Royal College of Occupational Therapists Guideline Review Group, are reviewing the practice guideline *Occupational Therapy in Neonatal and Early Intervention*. We'd like your help in making sure the guideline's recommendations are clear and make sense.

Occupational therapists provide practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them. The Royal College of Occupational Therapists (RCOT) represents occupational therapists in all four UK nations, helping them to do their job and raise awareness of occupational therapy.

We have reviewed the most recent research evidence on occupational therapy care for babies born pre-term or high-risk and their parents. We have updated some of the guideline's recommendations, including adding some new ones – these cover infant pain management, infant massage and parent support. We'd like your thoughts on the recommendations by taking part in an online consultation survey. It does not matter whether you or your baby had occupational therapy support.

The survey has been reviewed and given approval through the RCOT project approval process. It has sixteen questions and should take approximately 10–15 minutes. Your responses are completely anonymous. We will use your answers along with other responses from occupational therapists and other relevant organisations to help amend the recommendations.

Your anonymous responses will be stored securely for three years.

The new practice guideline will be published in autumn 2022. Full details of the Royal College of Occupational Therapists' guideline development process, which has been accredited by the National Institute for Health and Care Excellence (NICE), are available in the *Practice guideline development manual* at: https://www.rcot.co.uk/node/293

If you have any questions, please contact Angie Thompson, RCOT Research and Development Officer: angie.thompson@rcot.co.uk or 0203 141 4615.

The recommendations cover occupational therapy services while babies are in the neonatal unit and receiving early intervention. If you feel upset by any of the questions and would like to talk to someone, you can contact your GP surgery for advice and information, or Bliss (charity that supports babies born prematurely or sick) https://www.bliss.org.uk/parents/support/emotional-support.

This survey is run through the Online Surveys JISCMail service https://www.onlinesurveys.ac.uk/. JISC is responsible for maintaining the security of the operating system used to provide online surveys and the JISC Online Security Policy applies (available at

https://www.onlinesurveys.ac.uk/help-support/online-surveys-security/). RCOT is the data controller for the information you provide in the context of this survey.

You as an individual have the right to decide whether to participate in this survey. All information collected about you will be kept strictly confidential. Generally respondents will be anonymous in the survey; contact details where specifically requested and provided are downloaded and stored separately to the survey data itself at RCOT on a password protected file and a code is used as a participant identifier. However, by logging into the JISC platform personal data in the context of GDPR will be processed by JISC to log users onto the site, session cookies and a unique identifier (UID) will be processed to manage the experience. All respondents will be anonymous in the analysis and published results.

Your data will only be viewed by the project team. The data will be processed through the JISC survey software and may be securely exported and analysed by RCOT or a Specialist Section or regional group acting on RCOT's behalf. Survey data will be stored for a maximum of 3 years after the survey conclusion and will be destroyed in accordance with the Royal College of Occupational Therapists Research Data Retention and Destruction Policy.

You have the right to access the information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection and data portability. Questions, comments and requests about your personal data may be sent to the RCOT Protection Officer at gdpr@rcot.co.uk. The RCOT Privacy and Data Protection policy can be viewed at https://www.rcot.co.uk/privacy-policy. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

Because the survey is anonymous, once you submit your response, it is not possible to withdraw because we will not know which response is yours.

1 **I have read the information, have had the opportunity to ask questions and agree to take part in the consultation.**

   a Agree: I wish to take part in the consultation. (Proceed to first page of survey)

   b Disagree: I do not wish to take part in the consultation

   IF DISAGREE TO TAKE PART:
   Thank you

   Thank you for considering taking part in the survey. You may now close your browser.

   IF AGREE TO TAKE PART:
   SURVEY QUESTIONS
   Information about you
   In this section, we would like to know a bit about you and your experience of your baby's care in the neonatal unit. This will help us to understand who is responding.

2 Did you or your family receive support or advice from an occupational therapist during or after your baby's stay in the neonatal unit?

   a Yes

   b No

   c Don't know

   d Prefer not to say

3 IF YES TO Q1: Do you feel you understand the role of an occupational therapist in the neonatal unit?

   a Yes

   b No

   c Don't know

   d Prefer not to say

4 What is your ethnic group? Choose one option that best describes your ethnic group or background

   a White (English / Welsh / Scottish / Northern Irish / British / Irish / Gypsy or Irish Traveller / Any other White background)

   b Mixed / Multiple ethnic groups (White and Black Caribbean / White and Black African / White and Asian / Any other Mixed / Multiple ethnic background)

   c Asian / Asian British (Indian / Pakistani / Bangladeshi / Chinese / Any other Asian background)

   d Black / African / Caribbean / Black British (African / Caribbean / Any other Black / African / Caribbean background)

   e Other ethnic group (Arab / Any other ethnic group)

   f Prefer not to say

Recommendation questions

The next three sections focus on the recommendations for different areas of occupational therapy practice. Please read the suggested recommendations and answer the following questions.

Pain management recommendations

1. ***It is recommended*** that occupational therapists promote the use of non-pharmacological pain management strategies (e.g. skin-to-skin care, facilitated tucking etc.) by all caregivers (parents and practitioners) for pain management during appropriate, planned, painful caregiving procedures.
2. ***It is recommended*** that occupational therapists support parent understanding and facilitate engagement in appropriate pain management strategies to enable them to provide sensitive support to their infants and promote parent self-efficacy.
3. ***It is recommended*** that occupational therapists work with the neonatal team to promote routine assessment of neonatal pain and identification of appropriate pain management strategies.

5 Do you think these recommendations on pain management make sense?

- a Yes
- b No
- c Don't know
- d Prefer not to say

6 Do you think these recommendations on pain management are clearly worded?

- a Yes
- b No
- c Don't know
- d Prefer not to say

7 If you responded 'no' to either of the two previous questions, could you explain why? OPEN RESPONSE

8 Are there any comments you'd like to make about the recommendations on pain management? OPEN RESPONSE

Infant massage and positive touch recommendations

1. ***It is recommended*** that occupational therapists facilitate the provision of positive touch and infant massage by parents/primary caregivers to decrease infant stress and improve state and physiological regulation.
2. ***It is recommended*** that occupational therapists facilitate the provision of positive touch and infant massage by parents to decrease parent anxiety and promote parent mood and parent–infant relationship.

9 Do you think these recommendations on infant massage and positive touch make sense?

- a Yes

b No

c Don't know

d Prefer not to say

10 Do you think these recommendations on infant massage and positive touch are clearly worded?

a Yes

b No

c Don't know

d Prefer not to say

11 If you responded 'no' to either of the two previous questions, could you explain why? OPEN RESPONSE

12 Are there any comments you'd like to make about the recommendations on positive touch and infant massage? OPEN RESPONSE

Parent support recommendations
1. ***It is recommended*** that occupational therapists support engagement in parenting occupations in the neonatal unit and following discharge (including, but not limited to, reading infant cues, guided participation in care, skin-to-skin, positive touch and holding) to promote decreased parent stress and positive improvements in parent–infant relationship and self-efficacy.
2. ***It is recommended*** that occupational therapists employ parent-focused interventions that incorporate parental sensitivity elements (e.g. reading infant cues and responding in developmentally appropriate ways) in order to reduce the psychosocial impact of delivering a high-risk infant, foster sensitive nurturing behaviour and promote the cognitive development of preterm infants.
3. ***It is suggested*** that occupational therapists engage parents in brief activity-based interventions during their infant's admission to the neonatal unit and that this can have a short-term effect in lowering parent anxiety.
4. ***It is recommended*** that occupational therapists employ the use of e-health interventions (e.g. web-based platforms, mobile apps, video conferencing etc.) to promote parent closeness and early parent-infant relationships.
5. ***It is recommended*** that occupational therapists employ the use of parent-focused psychosocial interventions to decrease parent stress and anxiety and promote parent coping, confidence and early parent–infant relationships.

13 Do you think these recommendations on parent support make sense?

a Yes

b No

c Don't know

d Prefer not to say

14 Do you think these recommendations on parent support are clearly worded?

a Yes

b No

c Don't know

d Prefer not to say

15 If you responded 'no' to either of the two previous questions, could you explain why? OPEN RESPONSE

16 Are there any comments you'd like to make about the recommendations on parent support? OPEN RESPONSE

Recommendations

17 Do you have any other comments you'd like to make about any of the recommendations? OPEN RESPONSE

Final page

Thank you very much for taking time to respond to this consultation. We really appreciate your help!

If you feel upset by any of the questions in the survey and would like to talk to someone, you can contact your GP surgery for advice and information, or Bliss (charity that supports babies born prematurely or sick) via https://www.bliss.org.uk/parents/support/emotional-support.

If you have any questions about the survey or the guideline, please contact Angie Thompson, RCOT Research and Development Officer: angie.thompson@rcot.co.uk or 0203 141 4615.

This survey is run through the Online Surveys JISCMail service https://www.onlinesurveys.ac.uk/. JISC is responsible for maintaining the security of the operating system used to provide online surveys and the JISC Online Security Policy applies (available at https://www.onlinesurveys.ac.uk/help-support/online-surveys-security/). RCOT is the data controller for the information you provide in the context of this survey.

You as an individual have the right to decide whether to participate in this survey. All information collected about you will be kept strictly confidential. Generally respondents will be anonymous in the survey; contact details where specifically requested and provided are downloaded and stored separately to the survey data itself at RCOT on a password protected file and a code is used as a participant identifier. However, by logging into the JISC platform personal data in the context of GDPR will be processed by JISC to log users onto the site, session cookies and a unique identifier (UID) will be processed to manage the experience. All respondents will be anonymous in the analysis and published results.

Your data will only be viewed by the project team. The data will be processed through the JISC survey software and may be securely exported and analysed by RCOT or a specialist section or regional group acting on RCOT's behalf. Survey data will be stored for a maximum of 3 years after the survey conclusion and will be destroyed in accordance with the Royal College of Occupational Therapists Research Data Retention and Destruction Policy.

You have the right to access the information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection and data portability. Questions, comments and requests about your personal data may be sent to the RCOT Protection Officer at gdpr@rcot.co.uk. The RCOT Privacy and Data Protection policy can be viewed at https://www.rcot.co.uk/privacy-policy. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

Because the survey is anonymous, once you submit your response, it is not possible to withdraw because we will not know which response is yours.

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Practice guideline
Second edition

This publication provides specific evidence-based recommendations which describe the best and most effective practice for occupational therapy for high-risk infants in neonatal and early intervention settings. It will assist decision making about areas for assessment and intervention, in addition to describing the profession's contribution to the neonatal care pathway. It may also be of use to other neonatal practitioners and commissioners with regards to the inclusion of occupational therapy within neonatal multidisciplinary teams.

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