

Developmental follow up of pre-term babies
Consultation on draft scope
Stakeholder comments table
29 May 2015 – 26 June 2015

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Alder Hey Children's NHS Foundation Trust	General	General	It must be emphasised that the collaboration between neonatal intensive care units and paediatric neurology and community child health services in England and Wales is poor and in many geographical locations is embarrassingly non-existent. This is in sharp contrast to Canada and the USA. There is the generally well-held view that neonatal paediatricians (neonatologists) are poor at involving other specialities and particularly paediatric neurologists. They rarely seek specialist advice on neonates born prematurely who experience a range of acute neurological complications whilst still on the neonatal intensive care units and are equally poor at pro-actively engaging with paediatric neurology and community disability services for those children that are known to be at high risk of developing neurological and developmental sequelae because of their prematurity. The same applies to the use of 'NIDCAP' and Brazelton (neonatal behaviour) approaches for all healthcare professionals involved in the care of neonates born prematurely. This again is in marked contrast to the situation in Canada, the USA and Scandinavia. In much of England and Wales there is poor or no 'joined-up' thinking / practice for these high-risk infants and their families.	Thank you for your comment. As part of this guideline development we will be looking at how information should be shared between organisations delivering NHS commissioned health care and also between the NHS and schools and also what is the most appropriate model (including setting and personnel) for service delivery.
Association of Child Psychotherapists	General	General	The guidelines cover developmental problems and disorders in babies, children and young people under 13 years, who were born prematurely, taking into account material, neo-natal and societal factors that might affect their risk. It also mentions which healthcare professionals are responsible for the identification, assessment and follow- up arrangements	Thank you for your comments. We will be looking at the experience from both the children and young people's perspective and the parent and carer as outcomes for the guideline evidence reviews. We will also be looking at risk including adverse neonatal experience and any evidence of effective interventions. We will also recruit lay members (parents and carers

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			<p style="text-align: center;">Please insert each new comment in a new row</p> <p>for these children. Our comments address some of these factors and then how the later disturbance can be identified and understood.</p> <p>There are a number of particularly traumatic neo-natal experiences and then there is the question of how to support these children and their families as the child grows. These might include babies that have particularly painful or near death neo-natal experiences, and babies that have had to withdraw from drug addiction. Of course babies respond to these difficult experiences in unique ways and there can be no 'correct' way of assuming what that experience has been. The observations of health professionals and parents can give us an idea of what a particular baby has been through. But it may, at times, be hard for staff and parents to really register the distress of the baby as this can be very upsetting to witness. Their capacity to do so may be helped by staff support meetings and by parent support work.</p> <p>This understanding of what the baby has gone through is vitally important in understanding later behavioural and emotional disturbance. What may seem like baffling behaviour becomes more understandable</p>	<p style="text-align: center;">Please respond to each comment</p> <p>of preterm children) and a multidisciplinary guideline committee which will bring their experiences of observing preterm babies to the discussion of available evidence.</p>

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			<p style="text-align: center;">Please insert each new comment in a new row</p> <p>when we reflect on what the child went through as a baby. But it is very hard to make this observational material available. The parents may, for very understandable reasons, not have been able to be with the baby in hospital very much or the baby may have gone from the hospital to fostering and then on to adoption. So the verbal story of the hospital experience may get lost. Also chaotic babies are more likely to have a string of carers and so again the link to early experience gets weakened or lost.</p> <p>The hospital notes on babies tend not to give fine observations which help us to enter the experience of the new baby. Child psychotherapists are uniquely trained to observe babies, to stay with painful experiences, and to try to make sense of what they see. They are also trained to think about a child or young person's baffling behaviour at least in part in terms of early infantile experience.</p> <p>Therefore, the Association of Child Psychotherapists (ACP) advocates the close observation of distressed pre-term babies and the use of these observations in understanding later developmental problems, emotional difficulties and distressing behaviour. The</p>	Please respond to each comment

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			ACP believes that at all of these stages child psychotherapists are an essential part of the team.	
Association of paediatric anaesthetists of GB and Ireland	General	General	This is a well-written scope and identifies an area that could have a huge beneficial impact on the long-term care of children with developmental issues. The improved survival of more and more extreme premature babies does come at a considerable cost not only in the impact it has on the life of parents and carers but also on the lifelong financial burden it places on parents, carers, individual health boards and Trusts and the wider NHS. Work on the development of this guideline is to be welcomed and it is hoped that this will help direct funding more effectively and with greater efficiency in the future.	Thank you for your comment.
Association of paediatric anaesthetists of GB and Ireland	General	General	The preterm cohort has obvious health needs but term newborns having cardiac surgery have a similar spectrum of problems and needs (Beca 2015) and would benefit from a standard follow up. Is it possible to amend the scope to include special groups such as this, many of whom are born post 37 weeks gestation, would fall outside the scope of this guideline but actually present the same clinical and societal problems.	Thank you for your comment. Unfortunately, this is outside of the remit of this guideline.
Association of paediatric	General	General	As anaesthetists our involvement here is a little tangential however given the concerns expressed	Thank you for your comment. The issue of risk factors (including during the neonatal period) will be

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anaesthetists of GB and Ireland			recently in a few publications regarding the impact of some anaesthetic agents on the developing brain of neonates and small children and potential for longer-term consequences this should be a background consideration during this guideline development. A number of studies are on-going in this area though the outcomes and conclusions are necessarily some time away. This guideline does however offer the opportunity to prospectively plan to record anaesthetic and surgical interventions and to assess a contribution, if any, to subsequent neurodevelopment. These children often have repeated exposure to anaesthesia and surgery, anaesthetists are concerned about the developmental effects of anaesthesia in early life and would support prospective data collection around this topic in this group.	discussed with the guideline committee during agreement of the relevant evidence review protocol.
Association of paediatric anaesthetists of GB and Ireland	General	General	Variation in follow up between regions is the norm and the lack of data frustrating. The ability to track each patient through healthcare is crucial and the investigations and developmental assessments should be routine.	Thank you for your comment. This guideline will aim to reduce variation in follow-up by reviewing the best available evidence to inform recommendations on the most appropriate model for service delivery for the identification and monitoring of developmental problems and disorders.
Bliss	General	General	Bliss welcomes the breadth of the draft scope of the guideline. The issues and key areas listed in the draft scope are all inter-related so it is vital that the guideline does not exclude any of these.	Thank you for your comment.
Bliss	2	35-39	We believe it is important that all settings in which NHS or local authority commissioned healthcare is provided,	Thank you for your comment.

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			including educational settings, are covered by the guideline.	
Bliss	2	28-29	It is also welcome that babies, children and young people from birth up to the age of 13 are covered by the guideline. The areas listed in the draft scope are highly relevant from birth and continue to be important for many pre-term children and young people, and their parents, throughout their childhood and into adolescence as many will continue to have developmental problems and needs for support as they get older.	Thank you for your comment. Please note that following stakeholder consultation the upper age limit for this guideline has now been changed to under 18 years of age.
Bliss	4	95-102	The inclusion of information provision as a key issue is particularly important, especially the question of the most effective approach to share information between organisations delivering NHS commissioned health care and schools.	Thank you for your comment. The topic you have mentioned on sharing information is included in this guideline.
Bliss	4	100	<p>However, Bliss recommends widening the scope of this question to include school admission authorities.(1)</p> <p>Many children born pre-term are not ready to start school at the same time as full-term children their age. This can be a particular issue for premature summer born children who fall into a different year group to the one they would have been in if they had been born full-term. Research has shown that starting school before they are ready can have a significant negative impact on children born pre-term, including by putting them at an educational disadvantage and increasing their need</p>	Thank you for your comment. As part of this guideline development we will be looking at how information should be shared between organisations delivering NHS commissioned care and also between the NHS and schools.

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			<p>for special needs support.(2)</p> <p>Evidence provided by health care professionals about the child's development can be crucial when admission authorities take a decision on whether to allow parents to delay their child's reception start date by one year. This means that information sharing between organisations delivering NHS commissioned health care, schools and admission authorities can have a clear impact on several of the main outcomes to be considered in the development of this guideline, including quality of life, social functioning and educational attainment.</p> <p>(1) In the case of foundation, voluntary aided schools, academies and free schools the school is the admission authority, but for community and voluntary controlled schools the local authority is the admission authority.</p> <p>(2) Odd D., Evans D. and Emond A. (2013) Preterm birth, age at school entry and educational performance Morse S., Zheng J., Tang Y., and Roth J. (2009) Early school age outcomes of late preterm infants. Paediatrics, 123(4):622-699 Huddy C., Johnson A. and Hope P. L. (2001) Educational and behavioural problems in babies 32–35 weeks gestation. Archives of disease in childhood - fetal and neonatal edition, 85(1):23-28 Johnson S., Hennessy E., Smith R., Trikić R., Wolke D. and Marlow N. (2009) Academic attainment and special educational needs in extremely preterm children at 11 years of age. Archives of disease in childhood - fetal and neonatal edition,</p>	

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			94(4):283-289	
College of Occupational Therapists	General	General	<p>The College of Occupational Therapists welcomes the opportunity to provide comment on the guideline scope for the development of a clinical guideline on the developmental follow-up of preterm babies.</p> <p>The provision of services to preterm infants and their families has been a recognised and core component of occupational therapy practice for in excess of twenty years. Services to this client group are provided within neonatal units, within formal preterm infant developmental follow-up services, and in general paediatric community settings. The level and type of monitoring and support routinely provided to infants born prematurely has been inconsistent and we therefore welcome the development of a NICE clinical guideline to provide appropriate review of the evidence and subsequent recommendations for practice.</p>	Thank you for your comment. We have signposted variation in provision in the developmental follow-up of preterm babies, children and young people and we will be reviewing the best available evidence to inform recommendations for the NHS.
College of Occupational Therapists	General	General	The most significant concern identified by the College of Occupational Therapists following the original publication of the consultation was the exclusion of occupational therapy as a recognised profession in the establishment of the guidelines development group. As outlined in point 2, the evidence base demonstrates that preterm infants are at very high risk of neurodevelopmental impairment particularly in the cognitive, emotional, behavioural, sensory and physical domains. These issues often become most evident during the child's school years. Occupational	Thank you for your comment. We have now revised the guideline committee constituency to include an Occupational Therapist.

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			therapists are one of the few disciplines that are qualified to identify early deficits in all of these areas. Occupational therapists have specific expertise in not only recognising these deficits at an early stage, but also in providing intervention and support to remediate these deficits. Since the original publication of the guidance and following consideration of the feedback provided at the initial scoping workshop on 12 May, we are greatly appreciative that occupational therapy has now been included in the professional groups that will be recruited to form the membership of the guideline committee.	
College of Occupational Therapists	2	45-53	Given the breadth of impact that preterm birth can have on the function of an infant, child and young person in their range of occupational environments (home, school and leisure pursuits), we welcome the fact that guideline will not be specifically focused on monitoring and formal assessment of developmental milestones, but will also include a focus on information provision, support provision including anticipatory guidance, and recommendations for service delivery models with recognition of key health professions to provide identification, assessment and services.	Thank you for your comment.
College of Occupational Therapists	2	28-29	We welcome the proposal that the guideline will consider all infants, children and young people born at less than 37 weeks gestation. Many developmental follow-up programmes and services for preterm infants in the UK are	Thank you for your comment.

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			only able to provide formal follow-up for infants born at less than 30 weeks gestation or weighing less than 1000 grams at birth. However, as is outlined in the scope document, there is still a significant component of infants born between 30-37 weeks gestation that may experience developmental concerns that can significantly impact on their functional performance and developing independence. These children often present with milder or more subtle motor developmental concerns or cognitive, sensory processing and social-emotional/self-regulation concerns that become increasingly apparent as the children enter the nursery and school settings. It is these factors that most commonly result in a referral to paediatric occupational therapy services for assessment, specific intervention and ongoing support.	
College of Occupational Therapists	3	55-56	We note that the guideline scope document states that the management of disorders such as cerebral palsy will not be covered, and assume that this is due to the fact that separate guidance is under development for this clinical group (as per section 2.1). We would like to support that this is also a key area that requires evidence-based guidance for infants born preterm as access to services for these high-risk infants is inconsistent. The work of Action CP, a national consortium, is working to raise awareness of these discrepancies, including presentations to the parliamentary select committee.	Thank you for your comment. The recognition of cerebral palsy is one of the clinical areas in the guideline which is currently in development. Prematurity as a risk factor for cerebral palsy is being looked at as part of that guideline. For further information on the scope of the cerebral palsy guideline please see http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0687

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Department of Health	General	General	No comments	Thank you.
Guy's and St. Thomas' NHS Foundation Trust	general	general	There's no reference to the detection, assessment and management of behavioural and mental health difficulties. This is an important aspect of well-being and functioning. I understand that there is a separate guideline for this. However developmental problems and behaviour are often interlinked.	<p>Thank you for your comment. The remit of this guideline is on the follow-up of preterm babies with developmental problems and disorders. We will prioritise with the guideline committee which problems and disorders are to be looked at along with neurodevelopmental disorders such as ADHD, which is currently in the scope. We will also cross-refer to the following related NICE guidelines on the assessment and management of particular behavioural and mental health problems:</p> <p><i>In development</i></p> <ul style="list-style-type: none"> • emotional wellbeing in primary and secondary education. • mental health problems in people with learning disabilities <p><i>Published guidance</i></p> <ul style="list-style-type: none"> • social and emotional wellbeing for children and young people • pregnancy and complex social factors • autism guidelines on identification and management • diagnosis and management of ADHD in children, young people and adults • anxiety disorders

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				<ul style="list-style-type: none"> postnatal care
Guy's and St. Thomas' NHS Foundation Trust	general	general	Again guidance around timing of therapeutic intervention will be important for clinicians. A preterm baby could stay for months in the hospital and actually miss out on developmentally appropriate intervention. Who are best placed to provide this intervention?	Thank you for your comment. We will be looking at evidence in terms of what support should be provided to infants, babies, children and young people who were born preterm and to their parents or carers. Specific types of support will be prioritised with the guideline committee during agreement of the evidence review protocol.
Guy's and St. Thomas' NHS Foundation Trust	general	general	Guidance around early intervention to optimise development would be welcome. This also has implications for neonatal units- some units provide developmental care and others don't.	Thank you for your comment. We will be looking at evidence in terms of what support should be provided to infants, babies, children and young people who were born preterm and to their parents or carers. Specific types of support will be prioritised with guideline committee during agreement of the evidence review protocol.
Guy's and St. Thomas' NHS Foundation Trust	General	General	I am very pleased that NICE has taken up this guideline development which I think is long due. This guideline will help a large number of children in the community. I agree with rest of the draft document.	Thank you for your comment.
Guy's and St. Thomas' NHS Foundation Trust	2	41-44	Would this include type of care in the neonatal units? Some units provide proactive developmental care and others don't.	Thank you for your comment. We will be looking at evidence in terms of what support should be provided to infants, babies, children and young people who

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				were born preterm and to their parents or carers. Specific types of support will be prioritised with guideline committee during agreement of the evidence review protocol.
Guy's and St. Thomas' NHS Foundation Trust	2	28	It is not clear why 13 years of age, is the cut off for this guideline. Services in the Community often are designed around transitions points in education. Is this to include the first year in secondary schools?	Thank you for your comment. The upper age limit for this guideline has now been changed following stakeholder consultation to include young people up to 18 years of age.
Guy's and St. Thomas' NHS Foundation Trust	2	47	Should also include support while the baby is in the neonatal unit, e.g. enhance bonding, anticipatory therapy input, parenting advice. Hospitals are not the best place to develop and these babies often spend months in the hospital.	Thank you for your comment. We will be looking at evidence in terms of what support should be provided to infants, babies, children and young people who were born preterm and to their parents or carers. Specific types of support will be prioritised with the guideline committee during agreement of the evidence review protocol.
Guy's and St. Thomas' NHS Foundation Trust	3	73-76	Children born preterm often have multiple developmental problems, noticed at different ages, with compounding effects, possibly affected by their relatively poor executive function. They may or may meet the threshold for specific diagnostic labels. Without a specific 'label', school and parents struggle to understand these children, which I see as a 'Spectrum of Developmental problems	The guideline committee will take account of these complexities in their deliberations. They will also consider both developmental problems and disorders.

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			Preterm Children experience.'	
Guy's and St. Thomas' NHS Foundation Trust	3	71-72	Is this a suggestion that children who are born preterm could have different prognosis compared to children born at term for a given developmental disability?	Thank you for your comment. This clinical area will explore the prognosis of a child being born at different gestational ages.
Guy's and St. Thomas' NHS Foundation Trust	3	79	The frequency of developmental monitoring is not just dependant of gestational age. We need to know are there are other factors that inform us about frequency of developmental reviews- identified brain injury, sensory impairment noted in the neonatal unit. We also need information about age specific comorbidities and when to look for them. When do you stop correcting for prematurity.	<p>Thank you for your comment. We will be looking at evidence regarding age specific comorbidities when looking at the prognosis of specific developmental problems and disorders in babies, children and young people born preterm at different gestational ages.</p> <p>Following stakeholder consultation we have now included review questions on what and when corrections for prematurity should be made.</p> <p>We will be looking at factors other than gestational age as part of the following review question: What factors other than the degree of prematurity (for example maternal, neonatal, socioeconomic and environmental factors) influence the prevalence and prognosis of developmental problems and disorders in babies, children and young people born preterm? The list of factors will be prioritised with guideline committee during agreement of the evidence review protocol.</p>
Guy's and St. Thomas' NHS	3	82	This is a very relevant question. Currently neonatal units are obliged to follow-up	Thank you for your comment. We will be looking at this as part of the review question on how frequently

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Foundation Trust			children till 2 years of corrected gestational age. However, children who appear developmentally normal at 2 years of age, often present with learning, language and social interaction difficulties at school later on. Evidence about how confidently we could attribute their subsequent difficulties to prematurity would be helpful. Otherwise we might be running a battery of investigations to find a cause of their developmental problems. i.e. cost implication.	babies, children and young people born at varying levels of degrees of risk be monitored for the identification of developmental problems and disorders. We will consider your points when reviewing the evidence.
Guy's and St. Thomas' NHS Foundation Trust	4	85-87	This would be most helpful, because if there is good evidence, it will be a cost effective way for surveillance. Any evidence around the diagnostic value of teachers' concerns would be helpful for older children.	Thank you for your comment. We will be looking for evidence on problems that present at school age and we will include representation from education professionals on the guideline committee. All children are assessed at school entry but whether there is sufficient evidence for this to be helpful in preterm follow-up is as yet unclear.
Guy's and St. Thomas' NHS Foundation Trust	4	88-90	Any evidence of prognostic value of these developmental tools would be helpful in guiding early intervention and anticipatory support in schools.	Thank you for your comment. We will be looking at the prognostic value of developmental tools as part of this guideline.
Guy's and St. Thomas' NHS Foundation Trust	4	91-93	There is a contradiction in this statement. I am not sure if we can compare assessment	Thank you for your comment. We have modified this question following stakeholder consultation to read: <i>What is the diagnostic value of standard opportunistic</i>

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			tools with screening tools. Initial screening warrants further assessment. Screening suggests a problem and is not always diagnostic. The question is which tool helps us to identify genuine problems as early as possible and help with intervention.	<i>assessments (for example, the Healthy Child Programme [Department of Health 2009]) and validated developmental screening and assessment tools (used in primary and secondary settings) in identifying developmental disorders in babies, children and young people who were born preterm?</i>
Guy's and St. Thomas' NHS Foundation Trust	4	96-98	We need guidance to parents about 'red flags' to look out for and guidance that helps optimise development.	Thank you for your comment. Specific information on 'red flags' to look out for will be looked at as part of the evidence review on information provision.
Guy's and St. Thomas' NHS Foundation Trust	4	104	Guidance on how long and /or how often support should be provided would be useful. As well as guidance on who should provide this support.	Thank you for your comment. We will be looking at evidence in terms of what support should be provided to infants, babies, children and young people who were born preterm and to their parents or carers. Specific types of support will be prioritised with the guideline committee during agreement of the evidence review protocols.
Guy's and St. Thomas' NHS Foundation Trust	4	116	I would add age appropriately	Thank you for your comment. The different age groups to be looked at will be agreed with the guideline committee when discussing protocols for the evidence reviews.
Guy's and St. Thomas' NHS Foundation Trust	7	163-167	There is evidence to say that the preterm brain is not only susceptible to complex patterns of injury but also to a range of secondary maturational and trophic disturbances, both in the very preterm and	Thank you for comment. This has now been added to the key facts and figures section.

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			late preterm.	
Guy's and St. Thomas' NHS Foundation Trust	8	202	And screening is not done for long enough through the child's developmental period.	Thank you for your comment. We will be looking at the best clinical and cost effective evidence to inform developmental follow up to 18 years and at what ages different problems appear.
Guy's and St. Thomas' NHS Foundation Trust	8	210	2.5 years of age is too late from an intervention point of view to help optimise development, especially in high risk babies. There is an argument for anticipatory support to optimise development rather than wait and watch.	Thank you for your comment. We will look at the evidence for follow up at different ages and risk factors and if evidence is found for under 2.5 years of age then it will be considered. The 2.5 years assessment threshold is included as part of the Healthy Child Programme.
NHS England	General	General	The draft includes all babies born preterm. As risk of adverse outcomes doesn't rise that much down to 33w, mostly we recommend follow up for babies of 32 weeks of gestation or less. Indeed most neonatal services currently aim for $\leq 30w$ or $\leq 28w$. Clearly there is increased risk above 32 weeks but as these babies rarely come near an intensive care service and the pick up rate is very low we concentrate on lower gestations. This may be covered in your economic model but as the above is consistent with the DH Toolkit for Quality Neonatal Services (2009) it may be worth considering this before the scope is widened.	Thank you for your comment. As part of the protocols for the evidence reviews we will be agreeing with the guideline committee which stratification of the evidence should be done (i.e. based on gestational age and birth weight).
NHS England	General	218	Most follow up is done in specific neonatal follow up clinics or in general paediatric outpatients unless referral to community disability teams is required.	Thank you for your comment. We will carry out this follow up as part of the service delivery review questions. We agree.

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NHS England	4	114	These outcomes do not appear to cover the main outcomes associated with very preterm birth such as CP and learning difficulties which are reliably assessable, although I agree we need to look at social and wider outcomes	Thank you for your comment. This is not meant to be an exhaustive list and the final outcomes will be prioritised with the guideline committee when agreeing the evidence review protocols.
NHS England	6	General	Your draft pathway does not include the valuable use of the information for service planning, validation of unit performance and feedback to neonatal services about important outcomes to underpin their counselling strategy	Thank you for your comment. The draft pathway included in the scope is intended to mirror the key areas to be covered in the scope. Please also see section 1.3 (key area 5) of the final scope for details on service delivery which will be covered by this guideline development. We will also be seeking to appoint an expert witness in neonatal audit to provide expertise to the guideline committee.
NHS England	8	198	I would dispute the lifetime costs being mainly in the neonatal period for children with impairments such as CP. In the EPICure study such children had significantly increased costs (£30-55,000 in a single year)	Thank you for your comment. Based on the Mangham study the public sector additional costs to 18 years of preterm birth is 1.24 billion pounds. The relevant section in the scope has now been clarified.
NHS England	9	234	The NICE Quality Standard followed on from the DH Toolkit for Quality Neonatal Services (2009) in which longer follow up into school age was proposed as a goal. Key outcomes that concern parents of extremely preterm children include school entry and appropriate assessment at school age. Evaluating children at 2 years is poorly predictive of later outcomes on an	Thank you for your comment. As part of the guideline we will be looking at how frequently babies, children and young people born at varying levels of risk be monitored for the identification of developmental problems and disorders and until what age should babies, children and young people with born at varying levels of risk be monitored for the

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			individual basis, particularly because parents are better informed as to school age potential problems. We should therefore evaluate the potential for following high risk groups more closely. Evolving work in moderate/late preterm birth (e.g. LAMBS Study university of Leicester) indicates that a small number of children may have co-morbidities rather than a the whole group with reduced performance.	identification of developmental problems and disorders.
Royal College of General Practitioners	General	General	<p>The scope of developmental follow up of preterm babies before 37 weeks is enormous. The College respects the NICE methodology of looking at literature published on the subject and looks forward to the findings. (JA)</p> <p>The College would like NICE to evaluate the need to develop a prognostic model statistically combining various factors associated with poor longer term outcomes as proposed by Van't Hooft et al in their study of white mater abnormalities (WMA) on MRI on preterm babies. Van't Hooft J, van der Lee JH, Opmeer BC, et al. Predicting developmental outcomes in premature infants by term equivalent MRI: systematic review and meta-analysis. <i>Systematic Reviews</i>. 2015;4:71. doi:10.1186/s13643-015-0058-7" (MH)</p>	<p>Thank you for your comment. The breadth and depth of the scope will be managed with the guideline committee in terms of the criteria to be set in the evidence review protocols.</p> <p>We will consider the reference you provided once we initiate the development of this guideline.</p>
Royal College of Midwives	General	General	The RCM welcomes the draft of this important guideline and considers that the key issues	Thank you for your comment.

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			identified are appropriate.	
Royal College of Midwives	General	General	There should be a midwife member in the guideline committee as midwives are key to support and information giving during pregnancy and the early postnatal period. If this is not feasible due to limited size of the committee, a midwife should be brought in as an expert witness when discussing the information provision element of the guideline.	Thank you for your comment. A midwife role has been advertised as an expert witness for this guideline.
Royal College of Midwives	3	1.4	The stratification of risk according to gestation will be particularly useful.	Thank you for your comment.
Royal College of Nursing	General	General	The Royal College of Nursing welcomes the invitation to respond to this draft scope document. The RCN invited members who care for and/or have expertise for caring for babies and children and young people who were pre-term babies to comment on this draft document.	Thank you for your comment.
Royal College of Nursing	General	General	Our members consider that proposals to develop this guideline is timely providing improved focus on developing a healthy child towards healthy and emotionally secure adulthood. To this end our members consider that the guideline	Thank you for your comment. We agree and have added a reference to the NICE guideline on emotional wellbeing in primary and secondary education in the scope.

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			could include links to existing NICE guidelines for social and emotional wellbeing as it seems that there is a definite link between the guidelines, on infant mental health and the social and emotional welfare of children and young people.	
Royal College of Nursing	General	General	Our members welcome the proposal for the guideline to include areas beyond healthcare (social and educational, voluntary, arena as well) and with proposals that recommendations will complement existing national initiatives to promote social and emotional wellbeing within: Healthy lives, healthy people: our strategy for public health in England ; No health without mental health ; as well as the <i>Healthy Child Programme</i> .	Thank you for your comment.
Royal College of Nursing	2	120	Our members consider that the guideline also needs to make reference to: National Infant Mental Health Strategy and 'The First 1000 days'	Thank you for your comment. The national Infant Mental Health Strategy and 'The First 1000 days' do not have preterm babies as their focus and therefore we will not add these to the context section of the guideline scope.
Royal College of Nursing	2	120	The guideline also needs to include links to the following current NICE Guidelines and NICE Pathways as well as those in development: <i>Social and emotional wellbeing for children and young people overview:</i> http://pathways.nice.org.uk/pathways/social-and-	Thank you for your comment. We have added to the scope the related NICE guidelines and pathways that you mention and these will also be noted in the full guideline.

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			<p style="text-align: center;">Please insert each new comment in a new row</p> <p>emotional-wellbeing-for-children-and-young-people:</p> <p><i>Postnatal care overview:</i> http://pathways.nice.org.uk/pathways/postnatal-care</p> <p><i>Pregnancy and complex social factors overview:</i> http://pathways.nice.org.uk/pathways/pregnancy-and-complex-social-factors</p> <p>And currently in development:-</p> <p><i>Emotional wellbeing in primary and secondary education (update):</i> https://www.nice.org.uk/guidance/indevelopment/gid-phg82:</p>	<p style="text-align: center;">Please respond to each comment</p>
Royal College of Obstetricians and Gynaecologists	General	General	Thank you for asking the RCOG to review this scope. We feel that it reads very well and look forward to seeing the full draft in due course.	Thank you for your comment.
Royal College of Obstetricians and Gynaecologists	3	65	Will there be any stratification of follow up based on growth anomalies in pre-term babies – i.e are babies born with SGA pre-term at higher risk of neurodevelopmental disorders compared to appropriately grown pre-term babies – do they need a different follow up?	Thank you for your comment. Stratification based on the levels of risk will be discussed with the guideline committee and agreed during discussion of the evidence review protocol.

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Royal college of Paediatrics and Child Health	General	General	The scope excludes young people but 1.3 onwards includes young people; in addition 1.3.2 is not grammatical.	Thank you for your comment. The population covered has now been revised and the guideline will cover young people up to the age of 18 years of age.
Royal college of Paediatrics and Child Health	General	General	It may not be best use of this group to endeavour to determine outcome in groups of preterm infants. This is an area of much research and presents considerable difficulty. Certainly the work should reflect the findings of the large UK and international follow-up studies. The central messages that sadly long-term problems are not uncommon in the preterm infant, where the principal determinant is gestation at birth.	Thank you for your comment. We will aim to retrieve the best available clinical and cost evidence as part of this guideline development.
Royal college of Paediatrics and Child Health	General	General	It is clear that on follow-up: <ul style="list-style-type: none"> • Severe problems can be anticipated (cranial ultrasound, neonatal history); are detectable early; are always recognised by parents before professionals; are detected by any assessment of development. • Mild problems may only be apparent on late follow-up; are seldom anticipated; often require psychometric assessment; are usually noticed by parents first. (Common problems in the extreme prem like specific areas of learning difficulty are very difficult.)	Thank you for your comment. Your point will be considered during the discussion and agreement of the evidence review protocol for the review question on until what age should babies, children and young people with born at varying levels of risk degrees of prematurity be monitored for the identification of developmental problems and disorders.
Royal college of	General	General	The current system across UK is:	Thank you for your comment. We will endeavour to

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Paediatrics and Child Health			<ul style="list-style-type: none"> • haphazard • ill organised • nonuniform • not informed by evidence or need • not centred around the child and family (compare the regular attendance for family massage group with the DNA rate for routine neonatal follow-up clinics) 	address variation in care provided and uncertainty in best practice by identifying the best available clinical and cost evidence and during agreement of recommendations with the guideline committee. The guideline committee will include 2 lay members which will also work towards ensuring recommendations are child and family centred.
Royal college of Paediatrics and Child Health	General	General	<p>Can we justify hospital attendance (transport, cost, disruption for the family) for neonatal follow-up?</p> <p>The cost benefit of such a system has not been assessed. The driver for any follow-up should be the needs of the child.</p>	Thank you for your comment. We will be looking at the most appropriate model (including setting and personnel) for service delivery for the identification of developmental problems and disorders in babies, children and young people born preterm. This will mean both reviewing clinical and cost data available.
Royal college of Paediatrics and Child Health	General	General	Any system for detection of problems must have access to established pathways referral and intervention.	Thank you for your comment. The guideline committee will look at this when developing recommendations as part of this guideline development.
Royal college of Paediatrics and Child Health	General	General	We feel this is a useful exercise relating to an important area of practice, for which there is evidence of substantial underperformance at present.	Thank you for your comment.
Royal college of Paediatrics and Child Health	General	General	<p>The guideline will be useful in recommending minimum surveillance programme for preterm babies. However, the scope does not mention action to take when problems are identified.</p> <p>We suggest the guideline gives general guidance on</p>	Thank you for your comment. The care pathway will be outlined and the guideline committee will describe the most appropriate setting and personnel to do the developmental follow up as part of the development of the recommendations. Details on the transfer of care and pathways of referral will be for local

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			<p>action expected when problems are identified. Depending on the problem the usual action is referral to a paediatrician with expertise in Development (usually a 'community' paediatrician). The guideline may also give thought to transition of care from neonatal paediatrician (if this is the one undertaking initial developmental follow-up) to developmental paediatrician if/when problem identified.</p>	<p>commissioners and providers to establish. Please also see NICE guideline currently in development on the transition from children's to adult services http://www.nice.org.uk/Guidance/InDevelopment/GID-SCWAVE0714.</p>
Royal college of Paediatrics and Child Health	General	General	<p>The term 'developmental problems and disorders' is used throughout this guideline scope, and in medical practice (so it may be hard to avoid), but it is rather negative and can cause distress to parents.</p> <p>It would be better to refer instead to development that is different to that expected for an infant's or child's age. Although, often, this may mean that the infant or child has a developmental problem or disorder, the more neutral terminology is a better way to approach this issue and can be helpful in initial discussions with parents.</p>	<p>Thank you for your comment. We acknowledge the issue and have added an explanation to the scope to say that: <i>The term developmental problems is used to refer to the occurrence of developmental patterns different to those expected in babies born at term, for example feeding difficulties. The term development disorder is used to refer to specific conditions such as cerebral palsy or neurodevelopmental disorders, for example autism.</i></p>
Royal college of Paediatrics and Child Health	General	General	<p>It has been raised that particular attention needs to be paid to gestation banding. It may be that review of the literature suggests that the gestation bands into which this draft scope divides premature infants is not correct, in which case the guideline should not be bound by it. As we read the draft scope, it risks underplaying the significance of extreme prematurity.</p>	<p>Thank you for your comment. The guideline committee will consider your points when discussing the relevant evidence review protocols.</p>
Royal college of	General	General	<p>The draft scope should make it clear that a significant</p>	<p>Thank you for your comment. The guideline</p>

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Paediatrics and Child Health			<p>proportion of even severe disability will be detected (if detected at all) at school.</p> <p>Therefore, schools have a critical responsibility to understand the relative risk of learning problems, particularly in children who were previously born extremely preterm. We are concerned that the draft scope underplays the importance of this.</p>	<p>recommendations will not only be relevant to healthcare professionals, commissioners and providers of services for the developmental follow up of preterm babies, but it will also be relevant for educational services.</p>
Royal college of Paediatrics and Child Health	General	General	<p>We feel that some consideration should be given to whether the scope should include extremely growth retarded non preterm infants – what sort of developmental follow up is appropriate for such infants?</p>	<p>Thank you for your comment. Unfortunately, this is outside of the remit of this guideline.</p>
Royal college of Paediatrics and Child Health	General	General	<p>We are not convinced that including an OT on the guideline group is proportionate.</p> <p>The overwhelming majority of preterm infants do not have access to OT, and even access to physiotherapy surveillance is significantly incomplete.</p> <p>We therefore are concerned that the balance of the group may be excessively focussed away from the clinicians who will, very likely, continue to do the overwhelming majority of the follow up.</p>	<p>Thank you for your comment. We consider that having one OT member on the guideline committee is appropriate as we do think that they have a role in the developmental follow-up of babies, children and young people.</p>
Royal college of Paediatrics and Child Health	General	General	<p>We are not clear why only children under 13 years were included and not up to 16 years of age.</p> <p>We are, however, delighted that late preterms were</p>	<p>Thank you for your comment. Please note that following stakeholder consultation the upper age limit for this guideline has now been changed to until 18 years of age.</p>

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			<p>Please insert each new comment in a new row</p> <p>included i.e. 32-36 weeks gestational age as there is increasing evidence these children have increasing health care utilisation at follow up.</p> <p>Reference: <i>Johnson S, Evans TA, Draper ES, Field DJ, Manktelow BN, Marlow N, Matthews R, Petrou S, Seaton SE, Smith LK, Boyle EM. Neurodevelopmental outcomes following late and moderate prematurity: a population based cohort study.</i></p>	<p>Please respond to each comment</p>
Royal college of Paediatrics and Child Health	General	General	As only looking at children up to 13 years may miss neuropsychiatric conditions (which have a higher incidence in premature infants) that emerge at the time of puberty, meaning these children do not get adequate support (Epicure study)	Thank you for your comment. Please note that following stakeholder consultation the upper age limit for this guideline has now been changed to until 18 years of age.
Royal college of Paediatrics and Child Health	General	General	Statement "developmental problems" may be too vague for parents; could mention neurodevelopmental disorders more specifically e.g. autism, ADHD.	Thank you for your comment. We acknowledge the issue and have added an explanation to the scope to say that: <i>The term developmental problems is used to refer to the occurrence of developmental patterns different to those expected in babies born at term, for example feeding difficulties. The term development disorder is used to refer to specific conditions such as cerebral palsy or neurodevelopmental disorders, for example autism.</i>
Royal college of Paediatrics and Child Health	General	General	Consider risk stratifying premature infants on basis of cranial ultrasound scan results and offering more targeted support/ screening to those with high risk of impairment (research done at UCL by Professor Wyatt	Thank you for your comment. Stratification based on the levels of risk will be discussed when the guideline committee is formed and agreed during discussion of the relevant evidence review protocols.

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			has shown scans can be divided into low, moderate and high risk groups and predict level of impairment).	
Royal college of Paediatrics and Child Health	Page 3	line 73 - 76	The question should be extended asking also to what extent these factors influence outcome.	Thank you for your comment. That is implicit under prognosis.
Royal college of Paediatrics and Child Health	Page 3	Section 1.5	The scoping group should consider one additional question, i.e. whether there is evidence of early intervention making a difference in outcome to this cohort of children. Without this it will be difficult to perform a thorough economic evaluation of any proposed screening or surveillance programme.	Thank you for your comment. We will be looking at what support should be provided to infants, children and young people who were born preterm and to their parents or carers. The level of support will be prioritised with the guideline committee when discussing the relevant evidence review protocol.
Royal college of Paediatrics and Child Health	Page 4	1.5 (Part 3 Information provision and part 5 service delivery)	<p>The first bullet point stresses sharing information between NHS organisations and schools. However, we believe it should also be amended to include sharing of information within and between NHS organisations.</p> <p>From the National Neonatal Audit Programme audit question related to 2-year follow up of preterm infants the RCPCH has established that there is regional variation in capture of follow-up health screenings. There are many potential causes for this including ineffective communication between neonatal services that know which preterm infants require follow-up and the local health services teams that actually carry out the follow-ups.</p> <p>The reverse may also attribute to the current</p>	Thank you for your comment. We have revised the evidence review questions under information provision following stakeholder consultation to acknowledge this.

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			predicament where local follow-up services do not feedback results of screening to the neonatal services which have cared for the preterm infants after birth. Either part 3 or part 5 could be edited to reflect the need for establishing proper communication pathways between health organisations that identify the infants requiring health follow up and the health organisations that carry out health screenings.	
Royal college of Paediatrics and Child Health	Page 4	line 107	Add question to section: Who should do the assessment and what training is required to perform assessments? E.g. Bayley III requires quite an extensive training.	Thank you for your comment. The guideline committee will address the most appropriate setting and personnel that should be conducting the assessment as part of the development of the recommendations including reference to skills required.
Royal college of Paediatrics and Child Health	Page 4	line 111, point 1.6	Consideration should be given to the assessment of the impact of prematurity on adult physical (and mental) health, i.e. early onset of adult diseases as seen e.g. in growth restricted infants	Thank you for your comment. Following stakeholder consultation it has been agreed that the upper age limit for this guideline would be revised from 13 years to 18 years of age. However, the assessment of the impact of prematurity on adult health it outside of the remit of this guideline.
Royal College of Speech and Language Therapists	2	4	Parent-Child Interaction needs to be referenced: Eyberg et al, 1995. Parent-Child Interaction Therapy: a psychosocial model for the treatment of young children with conduct problem behaviour and their families. <i>Psychopharmacology Bulletin</i> .	Thank you for your comment. This will be referenced in the guideline as a key paper for the relevant evidence review protocol.
Royal College of Speech and Language	2	4	We think you need to add "eating and drinking difficulties "after the "help with" as these problems are very prevalent in this group (Rommell et al, 2003. The	Thank you for your comment. This has now been clarified in the scope key issues and draft review questions.

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Therapists			complexity of feeding problems in 700 infants and young children presenting to a tertiary care institution. <i>Journal of Pediatric Gastroenterology and Nutrition</i> , 37(1); pp 75 - 84	
Royal College of Speech and Language Therapists	4	118	We think it might be better to use the term "child" here rather than "patient".	Thank you for your comment. This has been revised.
Royal College of Surgeons	General	General	No comments	Thank you.
Sheffield Teaching Hospital NHS Foundation Trust	4	88 109	There is a strong emphasis on the use of developmental assessment tools and service delivery to support diagnosis, identification and assessment of developmental problems. Does the scope of the guideline extend to assessment tools and/or service delivery that facilitates intervention and supports parents and families in early development?	Thank you for your comment. We will be looking at what problems and disorders occur in preterm babies over and above those in term babies but the diagnosis and management of any problems and disorders is outside of this guideline remit and thus reference will be made to other NICE guidelines.
Thames Regional Perinatal Group	General	general	To include all babies from birth	Thank you for your comment. We consider that this is clear in the scope.
Thames Regional Perinatal Group	general	general	SEN and educational psychologists to be involved	Thank you for your comment. We agree and have advertised for an educational psychologist to be part of the guideline committee.
Thames Regional Perinatal Group	general	general	NHS numbers of babies have to be included in order to trace children	Thank you for your comment. The guideline committee will consider this when developing recommendations for this guideline.
Thames	general	general	Methodology- national data collection and coordinators	Thank you for your comment. However that is outside

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Regional Perinatal Group			at the clinical reference group level and Badgernet to be made available in the community	of the remit of a clinical guideline.
Thames Regional Perinatal Group	4	114	Quality of life- outcomes – growth parameters, respiratory outcomes- babies with tracheostomies, with pulmonary hypertension, babies with stomas, babies with neonatal seizures and ventriculoperitoneal shunts	Thank you for your comment. This list is not meant to be an exhaustive list of outcomes and will be discussed with the guideline committee during discussion of the evidence review protocol.
Thames Regional Perinatal Group	4	115	Social functioning- behavioural problems, problems with attention	Thank you for your comment. This list is not meant to be an exhaustive list of outcomes and will be agreed with the guideline committee during discussion of the evidence review protocol.
Thames Regional Perinatal Group	4	118	Patient experience- iatrogenic consequences	Thank you for your comment. This list is not meant to be an exhaustive list of outcomes and will be agreed with the guideline committee during discussion of the evidence review protocols.
Thames Regional Perinatal Group	7	189	At corrected age of 2 years	Thank you for your comment. The evidence regarding the correction for gestational age is part of our evidence review questions.
University College London Hospital NHS Foundation Trust	3	82	The scope should identify "From what age until what age". I believe it should start at birth.	Thank you for your comment. We have revised the upper age limit to 18 years of age following stakeholder consultation. The guideline will also include babies from birth.
University College London Hospital NHS Foundation Trust	4	114	The main outcomes should be classified on intervals according age corrected for prematurity and should include outcomes during admission to NICU (on monthly bases until discharge), at discharge, at three months, at 1 year, at 2 years, at 5 years and at 11 years.	Thank you for your comment. This list is not meant to be an exhaustive list of outcomes and will be agreed with the guideline committee during the discussion of the evidence review protocols. We will also consider your points during the searches

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Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			<p>So when searching the evidence terms that should be included are:</p> <ul style="list-style-type: none"> - Survival - Growth weight, head circumference and length) and development (formal testing) - Need of oxygen - Feeding problems (food aversion) - Retinopathy of prematurity - Squint - Hearing loss - General movements (specific at term and three months) - Neurology examination or assessment - Development - 	for this guideline.
University College London Hospital NHS Foundation Trust	4	118	The search should include conditions as consequence of treatment (like surgical NEC) or iatrogenia (loss of fingers, scars, nasal deformities) during admission to NICU	Thank you for your comment. We will consider your points during the searches for this guideline.
University College London Hospital NHS Foundation Trust	4	119	<p>Parent experience in NICU</p> <ul style="list-style-type: none"> - In NICU - skin to skin contact or kangaroo care - - breastfeeding support - - involvement in treatment 	Thank you for your comment. We will look at support with eating and drinking difficulties, parent child interaction and continuation of breast feeding as appropriate. The final list of what support will be looked at as part of this guideline will be agreed with the guideline committee during the discussion of the evidence review protocols.

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