Developmental follow-up of children and young people born preterm
Consultation on draft guideline - Stakeholder comments table
[20/02/2017 to 03/04/2017]

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Association of paediatric chartered physiotherapists	Full	12	28-31	Add: optimising baby's motor skill development	Thank you for your comment. As this recommendation is about support for parents, not professional interventions, this was included but the wording was changed to cover physical positioning of the baby.
Association of paediatric chartered physiotherapists	Full	13	10	Healthcare professionals providing postnatal care and support in the community for babies born preterm should have the skills and knowledge to recognise and manage problems in these babies, including: 'Optimising motor skills development'	Thank you for your comment. As this recommendation is about concerns after discharge, the committee did not feel it was appropriate to add this language here, but have made recommendations on the professional skills required in the follow-up teams.
Association of paediatric chartered physiotherapists	Full	14	40-43	Recognise the following as possible early motor signs of cerebral palsy: Line 40. suggest adding 'unusual and absent fidgety movements' Line 43. abnormalities of tone including hypotonia (floppiness) or spasticity Suggest adding ' or 'Transient dystonia of prematurity'	Thank you for your comment. The first two suggestions have been implemented. The committee did not add 'transient dystonia of prematurity' as the committee concluded this was not a definitive sign of cerebral palsy.
Association of paediatric chartered physiotherapists	Full	24		Repeated question	Thank you for your comment. These questions are not repeated: one question relates to problems and one relates to disorders.
Association of paediatric chartered physiotherapists	Full	244		The way that some of the findings are summarised is quite confusing in its currently very textual format could it be summarised in tabular form.	Thank you for your comment. There is a large amount of evidence in some of the reviews and navigating through all the evidence statements is understandably quite challenging. The findings are also presented in summary in the forest plots in Appendix J, and in table 15 in the Full guideline document and in more detail in the evidence tables in appendix K.
Association of paediatric chartered physiotherapists	Full	607		Identifies use of Abnormal Involuntary Movement Scale (AIMS) is this meant to be The Alberta Infant Motor Scale.	Thank you for your comment and noticing the mistake. We have now corrected this to the Alberta Infant Motor Scale.
Association of paediatric chartered physiotherapists	Full	626	27	Suggest adding **'Optimising the baby's motor skill development'**	Thank you for your comment. As this recommendation is about support for parents, not professional interventions, this was included but the wording was changed to cover physical positioning of the baby.
Association of paediatric chartered physiotherapists	Full	627	32	Suggest adding **'Optimising the baby's motor skill development'**	Thank you for your comment. As this recommendation is about concerns after discharge, the committee did not feel it was appropriate to add this language here, but have included the professional skills needed in teams carrying out follow-up.
Association of paediatric chartered physiotherapists	Full	629	22 25	Recognise the following as a possible early motor signs of cerebral palsy. Unusual fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement. Suggest adding 'unusual or absent fidgety movements' abnormalities of tone, including hypotonia (floppiness) or spasticity (stiffness). Suggest adding 'or transient dystonia of prematurity'	Thank you for your comment. The first two suggestions have been implemented. The committee did not add 'transient dystonia of prematurity' as the committee agreed this was not a definitive sign of cerebral palsy.
Association of paediatric chartered physiotherapists	General	General		The guidelines layout the minimum requirement for follow up it would be useful and desirable for the guidelines to recommend the gold standard of practice. For instance the use of the Bayley III at 2 years. As some units already do far more than the minimum and others will only ever achieve the minimum.	Thank you for your comment. The aim of this guideline is to ensure all preterm babies receive appropriate developmental follow-up, and as such we have recommended the minimum requirement. This is with the aim of promoting equity across the country. Units who are already exceeding this standard are welcome to continue providing the excellent services they may have already developed locally.
Association of paediatric chartered physiotherapists	General	General		Question 1: Communication and consistency of information is always fundamental. This is always very challenging where infants enter some community settings where there is insufficient knowledge of preterm/neonates and parents receive mixed quality of follow up. How does the reach of the guidelines permeate to such settings? Is there a plan for any tools to help some settings where their coverage is insufficient to	Thank you for your comment. We agree this is challenging but by initiating the follow-up to 4 years via the neonatal service and providing improved information and communication to parents about the developmental follow-up their babies/children will receive, and ensuring developmental follow-up is covered in discharge plans we hope this will improve. The follow-up and outcome will be

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				identify these gaps e.g. an audit tool such as laid out in the NICE spasticity Guidelines?	recorded in the National Neonatal Research Database which will allow coverage to be assessed.
Association of paediatric chartered physiotherapists	General	General		Question 2: It would be good to have clear laid out recommendations of assessment pathways to assess potential cost of training MDT teams.	Thank you for your comment. We have not been able to include the potential costs of training MDT teams in this guidance as there is currently so much variability in the composition of these teams.
Association of paediatric chartered physiotherapists	General	General		Question 1 and 2: These recommendations will mean a big change to the current delivery of physiotherapy services to high risk neonatal unit graduates across the UK. Currently neonatal physiotherapy services are inconsistent, patchy and variable across different trusts and areas of the UK. Few posts are funded, dedicated neonatal posts. Most posts are expected to combine neonatal follow up with a busy and varied caseload of children aged 0-19 in the community.	Thank you for your comment. We appreciate that there may be a requirement for increased physiotherapy services in some areas and hope this guideline will encourage increased commissioning of these services.
Association of paediatric chartered physiotherapists	General	General		Question 3: APCP has already published and established an evidence based guideline and competence framework for physiotherapists working across the UK, which outlines the necessary skill and expertise recommended to work in this specialist area.	Thank you for your comment. We are pleased to hear that the Association of Paediatric Chartered Physiotherapists is already looking to develop improved practice in this area.
Association of paediatric chartered physiotherapists	General	General		Question 2: It would be hoped that managers of neonatal networks and physiotherapy service managers acknowledge the economic evidence base of the cost effective savings to the services outlined in the full document in adopting these recommendations and use this evidence when preparing business cases in the future to ensure appropriate funding to be able to provide a specialist neonatal developmental physiotherapists as part of the neonatal follow up MDT in a dedicated role.	Thank you for your comment. We hope that the recommendations are useful to facilitate physiotherapy service developments as well. However, it should be noted that following stakeholder comments the cost analysis has been amended. Specifically, we have now assumed that a neonatologist and OT/physiotherapist would be likely to carry out the assessment at two years in both current and recommended practice. The cost analysis at two years has now been removed as there is no difference in personnel between the two approaches. This means that there are no longer cost savings at two years to outweigh the increased costs at four years. However, the cost at four years is thought to be justified by the potential to detect problems or disorders in this high risk group. It is hoped that by detecting these problems earlier, it will be possible to better manage them and improve QoL in those patients affected. Furthermore the cost of implementing the recommendation at four years is estimated to be £766,426 per year. This falls below the figure of £1 million per year which was deemed to constitute a significant impact according to NICE's resource impact policy.
Association of paediatric chartered physiotherapists	General	General		Question 3: it would be useful to look at the NNAP follow up data and see which units are able to produce the highest percentage of outcome data at 2years the national average is 54%.However the Edinburgh neonatal follow up service has 90% outcome data at 2 years. This could be used as an example of good practice.	Thank you for your comment. Yes, it is hoped that the changes to the 2-year assessment will improve follow-up rates and reduce variation in practice across England.
Association of paediatric chartered physiotherapists	General	General		Question 1: As part of Getting it right for Every Child (GIRFEC) all children in Scotland have a named person their health visitor until school age.	Thank you for your comment. This is a good example of high quality practice.
BLISS	Full	517-518	46-10	Bliss strongly agrees that discharge plans should be developed in conjunction with parents and that parents should be given information on caring for their child (such as information about feeding and sleeping) when leaving to refer to. However, to maximise parental confidence and promote bonding it is essential that parents are facilitated to be with their baby for long, uninterrupted periods of time so they can provide cares and comfort to their baby daily, as soon as it is medically safe to do so from admission to the neonatal unit – not just before discharge. The importance of empowering parents to take the lead in their baby's care needs to be captured in the recommendations.	Thank you for your comment. The recommendations include 'Help parents or carers to gain the knowledge, skills and confidence they need to look after their baby' and the committee agreed that this includes allowing the parents to look after their baby whenever possible.

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BLISS	Full	467	20-30	The evidence review of educational attainment has not included reference to the effect of starting school in the 'wrong' year group. This happens to children in England when they are born on or before August 31 when they were due after August 31. There is clear evidence to show that starting school in the 'wrong' year can compound existing developmental delays, and can lead to children requiring long-term academic support. When discussing developmental follow up, it is important to include an assessment of birth date to see whether the child will being starting school in a different year to the one they would have started in, had they been born full-term. Including this additional quick assessment can help highlight children who may need additional developmental support. (David Odd et al (2016)., *Preterm birth, age at school entry and long-term educational attainment,* PLOS one, accessed online: http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0155157 Quigley MA, Poulsen G, Boyle E*, et al* (2012) Early term and late preterm birth are associated with poorer school performance at age 5 years: a cohort study *Archives of Disease in Childhood - Fetal and Neonatal Edition* **97:**F167-F173. F6 of 7 states ''For a child already 'disadvantaged' by preterm birth or having a summer birthday, or the compound problem of starting school a year earlier than if they had been born at term, it may be appropriate to consider delaying school entry'' Johnson S, Hennessy E, Smith R*, et al* (2009) Academic attainment and special educational needs in extremely preterm children at 11 years of age: the EPICure study *Archives of Disease in Childhood - Fetal and Neonatal Edition*; **94:**F283-F289. ''Concern is frequently expressed regarding educational outcomes for [children who start school in the 'wrong' year] as the disadvantage already conferred by summer birth, due to age and length of preschool education may be compounded by premature school entry, a disparity that is never rectified throughout schooling…It may be advantageous to delay school entry, and to adopt admission rules based on corrected age.'')	Thank you for your comment. Although this is not addressed by a specific recommendation, the committee agreed that the risks and prevalence recommendations and the information and support recommendations all highlighted the problems associated with preterm birth and educational performance, and that children born preterm would follow an appropriate pathway into and through education, in the same way that any child with identified difficulties would, and that this pathway should be appropriate to the child's needs and not just reflect the fact that they were born preterm. The references mentioned were included in our reviews (please see section 4.2. and 4.4 in the Full guideline) apart from Johnson et al. 2009 which was replaced by a newer publication of the same study (Johnson, S., Wolke, D., Hennessy, E., Marlow, N., Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment, Developmental Neuropsychology, 36, 74-95, 2011).
BLISS	Full	473	1-3	Bliss agrees with the Committee's assertion that professionals working in the education and social care sectors need to be made aware of the developmental problems and challenges which children when they are born preterm. While this Guideline recommends that educational professionals are informed, with parental consent when a child is assessed as having a developmental need or disorder (Recommendation 44, page 630 line 10 in the full Guideline document) Bliss suggests that an additional recommendation is made that educational professionals, particularly Key Stage 1 and Key Stage 2 teachers where the impact of prematurity on attainment is most pronounced, receive active training and material to make them aware of how prematurity can affect learning. Information designed to equip teachers to support children born premature are available through the SSAT Complex Learning Difficulties and Disabilities Research packs: http://complexld.ssatrust.org.uk/project-resources/cldd-briefing-packs.html Around one in nine children are born premature in the UK every year. This means in an average class of 30 children, three will have been born premature, so it is essential that educational professionals are able to differentiate the curriculum effectively to support the needs of these children, and to support their ongoing learning and development. Yet evidence demonstrates that many teachers are	Thank you for your comment. We agree that teachers (especially in Key Stage 1 and Key Stage 2) should be aware of the effect of prematurity on learning. However, the committee agreed that children identified through the developmental follow-up process recommended in this guideline as having difficulties would follow an appropriate pathway into and through education, in the same way that any child with identified difficulties would, and that this pathway should be appropriate to the child's needs and not just reflect the fact that they were born preterm.

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				unaware of the effect prematurity can have on development, and many feel they need more training to support this significant minority of pupils (Johnson S et al. (2014) *The long-term consequences of preterm birth: what do teachers know?,* Developmental medicine and child neurology)	
BLISS	Full	475	19-27	Bliss recommends this particular recommendation should reference the impact school admissions can have on developmental outcomes, particularly in the early school years, if children start school a year before they would have done, had they been born full-term. Evidence for this is highlighted in Comment number 1.	Thank you for your comment. Although this is not addressed by a specific recommendation, the committee agreed that the risks and prevalence recommendations and the information and support recommendations all highlighted the problems associated with preterm birth and educational performance, and that children born preterm would follow an appropriate pathway into and through education, in the same way that any child with identified difficulties would, and that this pathway should be appropriate to the child's needs and not just reflect the fact that they were born preterm.
BLISS	Full	475	36	Terminology like 'oro-motor' may not be easily understood by lay members, including parents and carers of babies and children who were born premature. In order to ensure the Guideline recommendations are accessible, Bliss recommends including the definition of this term in brackets.	Thank you for your comment. The phrase has been amended to include '(for example sucking and chewing)' to clarify this.
BLISS	Full	476	15-16	Terminology like 'executive function' may not be easily understood by lay people, including parents and carers who may want to engage with the Guideline. As above in point 4, Bliss would recommend including its definition in brackets to make it clear what it means.	Thank you for your comment. Executive function has a complex definition which it is not suitable to put in brackets. However, the definition and explanation is included in the glossary and terms in both the long and short versions of the guideline.
BLISS	Full	477	5-6	This sentence references the stressful and busy environment of the NICU. Many babies born premature may not receive intensive care, but will be born needing high-dependency or special care instead. The number of babies spending weeks and months in intensive care is also relatively small – the majority who have a long-term stay will progress through all three levels of care. Bliss would suggest that 'NICU' in this sentence is changed to 'Neonatal unit' to reflect this.	Thank you for your comment. This change has been made.
BLISS	Full	477	8-9	As above in point 6, Bliss would recommend that the lack of facilities to keep families together is common at all centres which provide neonatal care, not just NICUs, so would again suggest that reference to 'NICU' is changed to 'Neonatal unit'. The lack of accommodation is a significant barrier to parents being able to participate in providing hands-on care to their baby, and the document is right to assert that this can leave parents feeling anxious and ill-equipped to care for their child. However, the shortage of sufficient facilities exists across all designations of unit, and separation and an inability to care for their baby affects all families – even those whose baby only needs to spend a short time in hospital.	Thank you for your comment. This change has been made.
BLISS	Full	517	33-41	Bliss agrees with the committee that how information is conveyed to families will vary widely from family to family, and that it is important to take into account the individual needs of the family when providing information. Bliss suggests that central to ensuring parents receive the best possible information is talking upfront with parents and asking how they would like to be told. All information discussed verbally should also be available in plain-English written form and parents given a single point of contact should they want to reflect further and find out more.	Thank you for your comments. We agree that information should be personalised and thank you for your suggestions on how it should be delivered. Providing an information in this way is recommended in the NICE guideline on NHS experience in NHS services which are cross-referenced from this guideline.
BLISS	Full	517	26-31	Bliss agrees that it is important when providing information to families to ensure that it is factual and honest without causing unnecessary worry and anxiety. However, it is important that parents receive the information they want and need in order to make fully-informed choices about their child's ongoing development and care. Bliss recommends that parents are supported to have an advocate or family-centred care lead present, if they would like this additional support, during these conversations to offer support and ensure understanding of the information conveyed.	Thank you for your comments. We agree that factual and honest information is key and thank you for your suggestions on how it should be delivered. Providing an advocate is recommended in the NICE guideline on NHS experience in NHS services which are cross-referenced from this guideline.
BLISS	Full	517	43-45	Bliss strongly agrees with the committee that information regarding developmental follow up is given to families by healthcare professionals with expertise in developmental follow up of children born preterm.	Thank you for your comment and agreement.

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BLISS	Full	518	16-19	Bliss strongly agrees that parents should be made aware of routine postnatal care and Healthy Child Programme, which still may be able to provide useful care and support while a baby is still an inpatient. However, it is important that these agencies are made fully aware of the challenges of neonatal care, and the impact on development being born premature can have. Bliss hears regularly from parents who are frustrated by services which do not understand neonatal care or prematurity. Sign-posting is only effective if the services are adequately equipped to care for these families sensitively.	Thank you for your comment. We agree that these services should be aware of the implications of preterm birth and neonatal care and hope the implementation of this guideline will assist in raising awareness and knowledge.
BLISS	Full	558	32-38	Bliss strongly agrees that feeding is essential to development and that post-discharge care in the community should include a practitioner with expertise in feeding issues. However, Bliss believes dedicated feeding support needs to be available to families on the unit from admission to build confidence and ability, rather than just highlighting its importance at discharge.	Thank you for your comment. The committee agree that feeding and nutrition are essential to development but the scope of this guideline relates to developmental follow-up and it is therefore not possible to cover in detail all other aspects of ongoing inpatient neonatal care. However, a single point of contact following discharge is recommended and a speech and language therapist has been added to the core multidisciplinary group.
BLISS	Full	558	16-20	Transitions are crucial times when parents need support, but it is important to recognise that not every transition from intensive care involves a transfer to another hospital or unit. Transfer to a different level of care (e.g. IC to HD or HD to SC) within the same unit can be difficult for families because they become accustomed to the level of support provided by nurses and other professionals when their child needs many interventions.	Thank you for your comment. We have added another recommendation to address the support issues needed at transition, as well as on discharge.
BLISS	Full	624	42-43	Bliss would recommend that a copy of any information about a child's development which have been shared with educational professionals (with parent's consent) should automatically be given to parents, rather than the onus being on parents to request it.	Thank you for your comment. The guideline contains a clear recommendation that information should also be shared with parents/carers.
BLISS	Full	625	44-46	Bliss agrees with the committee that if a problem or disorder is identified that the summary is shared with education services, with consent from parents, to ensure a development plan can be put in place for school services. However, Bliss would also suggest that sharing birth date is also considered, as per the evidence outlined in point one.	Thank you for your comment. The committee agreed that the expected birth date should be shared, and included a recommendation about sharing information with the parent's permission.
BLISS	Full	626	General	Bliss is extremely disappointed that the recommendations surrounding support and information to parents provides no detail on how to facilitate family-centred care to ensure parents are able to take the lead in providing their baby's daily comfort and cares as soon as clinically safe to do so. It is disappointing that recommendations focused on helping parents to 'gain knowledge, skills and confidence they need to look after their baby at home' is only discussed in the context of support which should be provided 'leading up to and on discharge.' As outlined in points 7 and 11, parental involvement as early as possible is essential to ensure the best outcomes for babies and their families. Parents cannot be expected to sufficiently develop confidence and knowledge in caring for their baby during the 'rooming-in' stage immediately prior to discharge if there has been limited opportunity for them to lead on their baby's care in the days, weeks or months prior to discharge planning. Bliss recognises that there is a shortage of practical facilities to support parents to stay at neonatal units across England. However the *Toolkit of High-Quality Neonatal Care* (2009) makes it clear that building parental confidence and skills needs to start at admission, not right before discharge. Bliss would urge the committee to consider a further recommendation to ensure parents are able to gain the knowledge, skills and confidence they need to look after their baby **from admission** to the neonatal unit.	Thank you for your comment. The committee agreed that support should be provided 'from admission…' and has added an additional recommendations stating this.

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BLISS	Full	626	21-22	Bliss would urge the committee to strengthen its recommendation which focuses on providing 'emotional and psychological support as needed' to include additional detail as to what this support should look like, and what parents should be offered. For example, the *Toolkit for High-Quality Neonatal Services* (DH and NHS England, 2009) and the *Service Standards for Hospitals Providing Neonatal Care* (BAPM, 2010) make it clear that counsellors and clinical psychologists should be available to parents with a baby admitted to NICU from admission.	Thank you for your comment. We have strengthened the wording of this recommendation so it now reads: 'Provide emotional and psychological support as needed to parents or carers of preterm babies, recognising the significant potential impact of having a preterm baby on all the family.' On implementation the information for the public will contain details of other sources of support for parents.
BLISS	Full	627	7-10	Bliss agrees with the recommendation to explain to parents at the time of discharge about corrected age and how this will be used in reference to development. However, discharge, while exciting, can be daunting and overwhelming and parents may not take in everything at once. Bliss would suggest that this recommendation is expanded to include a statement about providing parents with written information or a sign-post to an organisation such as Bliss which has information on corrected-age and development available on their website, so they are able to refer back to this.	Thank you for your comment and for your suggestions about how information should be provided. This is in accordance with the NICE guideline on NHS experience in NHS services which are cross-referenced from this guideline. The information for the public provided on the NICE website will contain additional sign-posting information and links.
BLISS	Full	627	16-17	While Bliss agrees it is important that parents and carers are made aware of the routine postnatal care and support which is available, particularly with regards to mother's follow up care, it is vital that these services are sensitive and flexible to the needs of families with a baby still receiving neonatal care for 8 weeks or more. It can be emotionally difficult for mothers to go to postnatal appointments and be asked questions about why her baby is not with her. Further, post-natal care should be transferred to the hospital where the baby is receiving neonatal care so mothers do not have to travel long-distances between different sites and miss out on valuable time with their baby.	Thank you for your comment. We agree with this comment but as the guideline is about developmental follow-up of preterm babies it is not within the scope to provide detailed recommendation on post-natal care.
BLISS	Full	628	1-7	Bliss agrees that babies born at late pre-term gestations should still be able to access enhanced developmental follow up, even if they do not meet the criteria discussed in recommendation 33. However, Bliss would suggest that the decision to provide developmental follow up should not be dependent solely on clinical judgement, but the decision made in conjunction with parents who are given the opportunity to discuss their concerns for their child's development. It should be recommended that clinicians take into account parental judgement.	Thank you for your comment. The committee felt that this decision would be primarily a clinical judgement, although it would be discussed with the parents and their concerns and views would be listened to, it would be a complex decision based on the balance of risks factors present and their severity.
BLISS	Full	628	9-11	This statement needs to be included in section Recommendation 29 (Page 627 / Line 7-10) so that parents whose baby fits the criteria for follow up are informed that this will happen before they are discharged from hospital. This is to ensure parents know their baby will be assessed at 2yrs and the request for follow up does not come "out of the blue" raising concerns that there is something wrong with their baby rather than realising it is routine practice. Many babies are not followed up for multiple reasons and lack of knowledge and change of location are two key areas which informing them at discharge would hopefully reduce.	Thank you for your comment. A new recommendation has been added to address this which states that parents and carers should be told whether or not their baby will be offered enhanced developmental follow-up and the plans for this follow-up.
BLISS	Full	629	2-18	With regards to the assessment at 4 years, it should also be considered whether the child's birth date has affected the timing of their admission to school, which may compound any developmental delays or disorders which are present.	Thank you for your comment. This recommendation relates to the problems and disorders, and as such the committee did not think it was appropriate to add this to the list.
BLISS	Full	630	20-40	Bliss would suggest, that this assessment at 4 years should also consider birth date for the reasons outlines above in point 24. It is also important for the assessors to keep in mind that when this 4-year assessment is being conducted that the child may already have started school, so it may be relevant to also discuss with parents about how the child is coping in that environment and if the parents feel that school has exacerbated any developmental issues they had noticed. This may contribute to the usefulness of information which can be passed onto education professionals, with permission of parents.	Thank you for your comment. The committee agreed that the 4 year assessment would include a parental assessment and discussion regarding the child's development, and this would include, if appropriate, a discussion of experiences at nursery or school.
BLISS	Full	632	11	By definition, all neonatal care *is* a specialist service. If this line is referring to children receiving intensive care, this should be explained clearly.	Thank you for your comment. All babies are neonates for the first month of life and therefore by definition will have had some neonatal care. By specialist neonatal care this means care in a neonatal unit.

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British Association of Perinatal Medicine	Full	General	General	This guideline is massive – the document feels as if it is a plan for research rather than a guideline for clinical use. It does not feel practical as a guide for those clinicians doing the follow-up.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate.
British Association of Perinatal Medicine	Full	General		I think this is a very important document. I agree that extending follow-up for preterm babies to 4 years is an important aim. However, the costs within this document are a significant underestimate. This is probably because the GDG clinicians are from centres of relative interest and excellence and therefore they do not have sufficient understanding of the general provision across the country. The costs will then escalate because Trusts will need to put in administrative support and presumably the % of babies where follow-up is achieved will then increase. For this guideline to be implemented a serious discussion will need to be had about the need for increased resources for neonatal care. How will it be funded?	Thank you for your comment and particular interest in the cost analysis. When the cost analysis was conducted, the guideline committee gave their best estimate of what most likely represented current practice across the country. However, there was known to be variation in practice and so there would always be differences between centres. An effort was made to capture the effect of these differences in sensitivity analysis. Note that, following stakeholder comments, revisions have been made to the cost analysis affecting the overall cost of implementing the recommendation. Specifically, we have now assumed that a neonatologist and OT/physiotherapist would be likely to carry out the assessment at two years in both current and recommended practice. The cost analysis at two years has now been removed as there is no difference in personnel between the two approaches. This means that there are no longer cost savings at two years to outweigh the increased costs at four years. However, the cost at four years is thought to be justified by the potential to detect problems or disorders in this high risk group. It is hoped that by detecting these problems earlier, it will be possible to better manage them and improve QoL in those patients affected. Furthermore the cost of implementing the recommendation at four years is estimated to be £766,426 per year. This falls below the figure of £1 million per year which was deemed to constitute a significant impact according to NICE's resource impact policy.
British Association of Perinatal Medicine	Full	562-575 586-589	14/15 19-24 Tables 49	The Schedule of Growing Skills is not considered further as there is said to be "no evidence" However this test is widely used and provides direct observations of the child's developmental skills as well as parental report. The choice of PARCA-R is surprising as it is a relatively unknown measure (and was not even considered as a measure of Child Development for the whole population.) The quality of the evidence for its use (Table 49) is rated low/very low with a serious risk of Bias. Only one study is rated of Moderate quality. Other widely used measures such as PEDS and Denver are not considered nor the more "Gold standard" tests such as Bailey and Griffiths. All children have an ASQ-3 at the 2 year check in the Healthy Child Programme therefore the addition of another parental questionnaire adds nothing to the Follow up of pre term babies. What is required is a test with an observational element that is therefore more objective.	Thank you for your comment. We consider it important that the recommendations are, whenever possible, based on evidence. As you say, no evidence was found on the accuracy of Schedule of Growing Skills tool compared to a standardised test tool in the preterm population. Therefore, we do not know how good a tool it is in this specific population. The evidence showed PARCA-R to correspond well with the standardised test (Bayley) among the preterm population. It also ensures involvement of the parents in the assessment. It was therefore considered appropriate as the minimum required tool to be used. The evidence on ASQ in the preterm population on the other hand showed less good accuracy compared to standardised tests. Units who are already exceeding the minimum standard set in the recommendations are welcome to continue providing the excellent services they may have already developed locally. Furthermore, the 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects including gross and fine motor development.
British Association of Perinatal Medicine	Full	603-605	14	Page 14 – onwards The economic argument for a screening test at 2 years rather than a structured assessment is the argument put forward for a structured assessment at 4 years. It is assumed in the guideline that 4 personnel including a clinical psychologist, are involved in the current practice of a structured assessment at 2 years, and that	Thank you for your comment and particular interest in the cost analysis. Following the stakeholder comments, the personnel assumptions made for the assessment at 2 years were revised. It has now been assumed that the assessment would involve an assessment by a neonatologist or paediatrician as

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				savings will be made by decreasing the number of personnel to 3. However, most of us only use 1 or 2 personnel (neonatologist and OT/physiotherapist) for our structured assessment (Bayley 3 assessment) at 2 years and there will be no financial saving that we can make for the enhanced surveillance at 4 years. We consider that most of our Trusts, like others, are very unlikely to put forward any money at all to do this at the age of 4 years.	well as an occupational therapist or physiotherapist. Therefore, under the new assumptions, the personnel would be the same in current and recommended practice, thereby rendering the cost analysis obsolete. As such, the cost analysis at two years has been removed. This means that there are no longer cost savings at two years to outweigh the increased costs at four years. However, the cost at four years is thought to be justified by the potential to detect problems or disorders in this high risk group. It is hoped that by detecting these problems earlier, it will be possible to better manage them and improve QoL in those patients affected. Furthermore the cost of implementing the recommendation at four years is estimated to be £766,426 per year. This falls below the figure of £1 million per year which was deemed to constitute a significant impact according to NICE's resource impact policy. It should also be noted that it is not anticipated that all members of the core team have to be present at each assessment. An amendment has been made to the recommendations to make this clear.
British Association of Perinatal Medicine	Full	6	18	Does the healthy child programme apply to the devolved nations? See also item 30, page 12 (NB typo in footer – Institute)	Thanks for your question. The Healthy Child Programme is only applicable to England, but the devolved nations have their own versions which are very similar. (Health Child Wales Programme, Child Health Programme (Scotland) and Healthy Child, Healthy Future (Northern Ireland). We have corrected the typo.
British Association of Perinatal Medicine	Full	11	13	Add section on other risks e.g. genetic or other identified factors giving a high risk of neurodevelopmental problems	Thank you for your comment. Evidence on a variety of risk factors was reviewed and the recommendations are based on the available evidence, but also allow for clinical judgement of likely risk. Please see a full list of risk factors that were considered in the review protocols for risk of developmental disorders and risk of developmental problems in Appendix D.
British Association of Perinatal Medicine	Full	11	21	Provide information about the risk and prevalence of developmental problems and disorders to parents or carers of preterm babies, and offer to discuss this with them I suggest only if parents wish discussion	Thank you for your comment. We have amended the wording of the recommendation to include the word 'offer' as suggested.
British Association of Perinatal Medicine	Full	13	25	This recommendation is completely unhelpful as it is far too vague. The guideline should either recommend an action based on defined criteria, or don't recommend anything.	Thank you for your comment. The wording of this recommendation has been amended but the committee agreed that there needed to be flexibility within the guideline to allow for children born preterm, who due to a range of risk factors, severity of risk factors or other reasons were deemed to be at increased risk of developmental problems, to be included in the enhanced developmental surveillance programme.
British Association of Perinatal Medicine	Full	13	35	I agree that parents should be given a single point of contact for follow-up. However, it does not need to be from the neonatal service if the follow-up programme is explicitly the responsibility of a paediatric or community team. The important point is that the parents have someone to go to, not which service hosts that point of contact.	Thank you for your comment. In order to ensure continuity of care the single point of contact will be from the neonatal unit, although preterm babies may also be followed up by the community paediatric team in some areas.
British Association of Perinatal Medicine	Full	14	9	Mention Baylee in this context (? Better than basic)	Thank you for your comment. Bayley Scales of Infant and Toddler Development is not included in the minimum requirements of developmental follow-up within the enhanced support and surveillance in this guideline.
British Association of Perinatal Medicine	Full	15	29	*Typo*	Thank you. This has been corrected.
British Association of Perinatal Medicine	Full	17	5, 7	I do not agree that the paediatrician or nurse that is involved in 2 year assessment requires expertise in neonatal care. They clearly need an understanding of what care the child had while in the neonatal unit and of the relevance of particular neonatal	Thank you for your comment. We have changed the wording to 'neonatologist or paediatrician with an understanding in neonatal care and child development'.

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				complications, but an understanding of a 2 year old and their development and care needs is much more important than neonatal competences.	
British Association of Perinatal Medicine	Full	17	19	Change paediatrician to practitioner with experience in child development it may well be appropriate in my opinion for this assessment to be undertaken by staff from education provided there is close collaboration with health	Thank you for your comment. The committee agreed that it was important to have a paediatrician involved in this assessment as it would require a medical assessment in addition to the psychological assessment.
British Association of Perinatal Medicine	Full	25		3.2.1 Clinical literature searches The following article should be added to the literature. The study cohort consisted of 1057 infants born at 22 to 25 weeks in the Neonatal Research Network, Japan. It also contains a section of systematic review, performed by using databases of publications of cohort studies with neonatal and neurodevelopmental outcomes at 22 and 23 weeks.; Ishii N[1], Kono Y, Yonemoto N, Kusuda S, Fujimura M; Neonatal Research Network, Japan. Outcomes of infants born at 22 and 23 weeks' gestation. Pediatrics. 2013 Jul;132(1):62-71. doi: 10.1542/peds.2012-2857. Epub 2013 Jun 3.	Thank you for your comment. The publication by Ishii et al. (2013) was considered for inclusion in reviews on the risk and prevalence of developmental problems and disorders according to the inclusion criteria set in the review protocols. The publication was not included in the risk of developmental disorders review for the following reason: the publication only reports the odds ratio for outcome "death *or* neurodevelopmental impairment" which was not an outcome of interest for the review according to the review protocol; furthermore, the reference group for this analysis was children born at 24 weeks' gestation whereas the reference group of interest according to the protocol was children born at term to which children born preterm would be compared. The publication was not included in the prevalence of developmental disorders review for the following reason: due to large amounts of evidence, the evidence on prevalence of developmental problems and disorders were narrowed down to Western settings (Europe, United States, Canada, Australia and New Zealand), therefore, the study by Ishii et al. (2013) from Japan was excluded. While the study was not included in the reviews for the above reasons, the evidence presented in the study on the prevalence of CP, cognitive impairment, hearing impairment and visual impairment among children born extremely preterm corresponds with our relatively large evidence base on these outcomes.
British Association of Perinatal Medicine	Full	589	8	Parca-R is completed by parents and sent electronically or through the post. The committee have acknowledged poor response rates – which are likely, and the possibility of filling them in when they come to a clinic. This would not only add time but would also introduce bias by using two different methods – postal questionnaires and face-to-face questionnaires are not the same.	Thank you for your comment. If not completed beforehand, PARCA-R can be administered by the parent(s) or carer(s) in the waiting room before the appointment. Filling in and scoring of the questionnaire are quick and simple, therefore, we did not consider this to introduce considerable time implications.
British Association of Perinatal Medicine	Full	604	20	I would like to know what evidence there is that 'current practice' for 2 year assessment on average across the country is to be doctor, ed psych, nurse and physio/OT. This estimation is fundamental to the financial calculations (ie cost saving of 'enhanced surveillance') and I think that it is likely to be a significant overestimate of current 2 year follow-up provision. If 'current practice' is either, for example, 1 person doing a Baileys or a Griffiths +/- a therapist, the costs of the recommended enhanced surveillance will be significant.	Thank you for your comment and particular interest in the cost analysis. As stated in the report for the cost analysis, the personnel involved was based on assumptions and was not evidence based. Furthermore, the estimate was not made with certainty as there was known to be variation in practice. Following the stakeholder comments, the personnel assumptions made for the assessment at two years were revised. Under the new assumptions, the personnel would be the same in current and recommended practice, thereby rendering the cost analysis obsolete. The cost analysis at two years has therefore been removed.
British Association of Perinatal Medicine	Full	606	1	Page 1 – onwards There is no estimation of the costs of running a follow-up scheme ie administration of appointments, chasing DNAs, trying to find babies lost to follow-up etc. This programme will require considerable infrastructure that has not been taken into account.	Thank you for your comment. The cost analysis provides an estimate of the personnel costs involved in follow-up. The analysis was not exhaustive and the committee were aware that there may be other costs not captured in the analysis, such as training and administration costs. It was not possible to formally include these aspects in the cost analysis because of a lack of resources and data.
British Association of Perinatal Medicine	Full	617	35	There is no estimation of the costs of collecting and administering data for audit as described, with the additional cost associated with 4 year surveillance data.	Thank you for your comment.

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					The finite guideline development time requires that certain aspects of the guideline are prioritised for economic analysis. The collection and administration of data for audit was not identified as a key priority for economic consideration and therefore no cost analysis was conducted in this area.
British Association of Perinatal Medicine	Full	618	28-39	By the assessment of the group itself, the PARCA-R may not detect mild to moderate disability well. Moderate disability often has a huge impact on families and it is imperative that it is picked up at 2 years, so that suitable support and resources can be put in place to help the child. If the definitive detailed test at 2 years, such as Bayley 3, is not done until 4 years of age, as is suggested, a significant amount of functional disability will have been missed and diagnosis of moderate delay will have been delayed. This is unfair on families.	Thank you for your comment. Recommending PARCA-R as the minimum aims to maximise the follow-up of these children and ensure parental input into the 2 year assessment. We agree that it is very important to identify and address mild and moderate disability. The 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects such as parental concerns, mild developmental delay or motor development.
British Association of Perinatal Medicine	Full	618	40	The recommendation is to offer a developmental assessment at 4 years. Neonatologists are not usually trained to do assessments at this age and the suggestion is that this is done by a paediatrician. Presumably this would need to be a developmental or community paediatrician – our resources would not allow this to be done and indeed the community paediatricians in most of our areas would have no time or desire in doing this for us. This may well be true for other trusts and is therefore impractical. Whose responsibility will this be?	Thank you for your comment. The assessment at 4 years will be conducted by an educational or clinical psychologist and a paediatrician with expertise in neurodevelopment. We hope the guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of staff to carry out this assessment.
British Association of Perinatal Medicine	Full	629	36	The guideline states that the PARCA-R should be used as a minimum – it does not suggest any other suitable alternatives.	Thank you for your comment. We recommend using the PARCA-R as part of a more comprehensive face-to-face assessment where other concerns can be raised and assessed and clinical assessment can be done. If the PARCA-R is not suitable then there are a number of other parent questionnaires which could be used.
British Association of Perinatal Medicine	Full	629	36	The PARCA-R is a parent questionnaire. Some parents have a tendency to over-estimate their child's ability.	Thank you for your comment. We consider it essential to have parent or carer involvement in the developmental assessment of the child. PARCA-R forms part of the assessment process which will include a full professional assessment.
British Association of Perinatal Medicine	Full	630		Section 46 Specific testing at 4 years with WPPSI this is a tool for psychologist (clinical/educational) which we do not have access to so whilst screening at 4 for high risk is possible and the SDQ can be used we do not have access to anyone who could administer the WPPSI. If this is to be specified would there be funding for small trusts that do not have access to this or would this be something to be looked at from a network perspective.	Thank you for your comment. We hope the guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of additional clinical or educational psychologists. The aim of the guideline is to reduce variability in services and ensure all preterm babies receive a minimum standard of developmental follow-up.
British Association of Perinatal Medicine	Full	618 & 589	28-39	As stated in the guideline, the downside of the PARCA-R is that it is not age-standardised and can only be used in a narrow-spectrum of 22-26 months of corrected age. This is impractical in a real life setting, as it is common for families to DNA or change the appointment date to a time outside of 22-24 months – there is no suggestion as to what tool to use then. Tools such as the Bayley 3 are usable at any age until 42 months.	Thank you for your comment. Indeed, PARCA-R is only validated in a relatively narrow timeframe. We hope that if parents and carers are clearly informed about the timeframe and the importance of it, it would not be a huge issue. However, if the assessment is missed within the timeframe, an alternative age-standardised parent questionnaire could be used. We leave it for the clinicians to decide which tool would be most suitable in these cases.
British Association of Perinatal Medicine	Full/short	General	General	It is great to offer the possibility of a further assessment at school age, but we don't feel it should be at the expense of the 2 years assessment.	Thank you for your comment. The assessment at 4 years is not intended to be at the expense of a detailed review at 2 years. There is still a detailed face-to-face assessment carried out at 2 years.
British Association of Perinatal Medicine	Full/short	General	General	Welcome the guideline and recognition of the issue of follow-up, which has been patchy and not standardised.	Thank you for your comment.
British Association of Perinatal Medicine	Full/short	General	General	Generally very supportive of document	Thank you for your comment, we are pleased to hear you are supportive of the document.

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British Association of Perinatal Medicine	Full/Short	General	General	The place of BSIII should be more clearly defined, as lots of units are using this, and it forms part of the BadgerNet data set. I assume that it is to be used as a diagnostic tool, if screening tools positive (?)	Thank you for your comment. Yes, Bayley III can still be used by units who are familiar with it and have competent practitioners to deliver it, but PARCA-R remains the minimum standard at age 2 to screen for problems and increase parental input into the 2 year visit and assessment.
British Association of Perinatal Medicine	Full/Short	General	General	Slightly anxious that NICE recommends screening tools (including PARCA-R), and then recommends research to explore their validity.	Thank you for your comment. The research recommendations on PARCA-R, ASQ-3 and SDQ were set to explore the predictive value of these screening tests to detect developmental disorders or problems at a later age. Whereas there is evidence on the diagnostic accuracy of these screening tests at the time of assessment (for example at 2 years), the ability for these tests to predict developmental disorders or problems at a later age (in preterm babies) is not known.
British Association of Perinatal Medicine	Full/Short	General	General	Overall, this is a useful document with lots of interesting background information. I suspect however too long for most neonatologists to read in great detail.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate.
British Association of Perinatal Medicine	Short	10	24	Separate cutoffs has been used for developmental surveillance for children born < 30 weeks and those born < 28 weeks. Would have been more practical to just use one cut off for surveillance till 4 years.	Thank you for your comment. The guideline committee carefully considered the gestational age cut-offs to enter the enhanced developmental support and surveillance up to 2 years' corrected age and up to 4 years of age. In the end, the committee had to consider the balance between cost and yield, bearing in mind that the absolute number of children born preterm increases with increasing gestational age. While we recognise that it might be more practical to have just one cut-off, there are evidence-based reasons for this decision. Evidence shows that children born before 30 weeks of gestation are at an increased risk of different developmental problems and disorders, and the committee agreed that they should be enrolled in the enhanced developmental support and surveillance up to 2 years of corrected age. At the same time, the committee agreed that for most children, severe developmental disorders and problems can be identified by 2 years of corrected age and therefore, developmental follow-up to identify these problems and disorders would be sufficient until 2 years of corrected age. However, evidence also shows that while the prevalence of special educational needs increases with decreasing gestational age, there is a clear additional increase in the prevalence of special education needs between 27 to 28 gestational weeks. Therefore, the committee agreed that children born before 28 weeks' gestation should receive enhanced developmental support and surveillance up to 4 years of age nearing the start of school.
British Association of Perinatal Medicine	Short	13	20-28	Helpful list of early motor signs of CP but these need to be recognised early and acted on. 2yrs or 4 yrs. would be late for early intervention in CP. Consider specifying age? 4 months corrected age.	Thank you for your comment. We have changed the recommendation to say that there should be a minimum of two developmental surveillance appointments in the first year of life, first between 3 to 5 months corrected age, and second by 12 months corrected age.
British Association of Perinatal Medicine	Short	13	1	The guideline does not specify what constitutes moderate or severe delay in specific developmental domains listed in 1.3.8 Page 13. This had been very clear and unambiguous in the previously published BAPM document "Classification of health status at 2 years as a perinatal outcome, 2008. Such clarification would allow for measuring outcomes of prematurity for audit, benchmarking and research purposes	Thank you for your comment. The list provided here is for screening purposes only and if any of the developmental problems or disorders listed are suspected, further investigations would then be necessary to confirm the diagnosis and define severity.
British Association of Perinatal Medicine	Short	13	16	Speech and Language Therapy should be included for enhanced development support at 2 years. Vital to identify early communication/language disorders. Early intervention and prevention vital and given high risk factors they should be integral to	Thank you for your comment. The committee has revised the recommendation and added speech and language therapist to the core multidisciplinary team delivering the assessment at 2 years corrected age.

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				team. Also Speech and Language therapists have enhanced skills in infant feeding disorders and reflux which should be integral up to 2 years.	
British Association of Perinatal Medicine	Short	14	19-22	Should be a caveat that says if developmental disorder or similar identified before 2 yr. assessment 'can be referred to local pathway at any stage before 2 years'	Thank you for your comment. The recommendations have now been amended so that it is now clear that if a concern of a developmental problem or disorder arise at any stage of the developmental surveillance, the child should be referred to the appropriate local pathway.
British Association of Perinatal Medicine	Short	14	9	This recommendation states that "at a minimum, Revised (PARCA-R) should be used" but does not state which developmental test is ideal or best suited (for example Bayley 3 or something else). The guideline seems to suggest that PARCA R should be mandatory however if some units are already using Bayley 3, then the guideline does not make it clear that PARCA-r is not necessary. Also, if the guideline is putting so much emphasis on PARCA-R , it should also clarify what score cut offs should be used to signify moderate or severe delay in non-verbal cognition and linguistic skills. Also, considering the high false positive rate of PARCA-r – the guideline should clarify what specific developmental test should be used to confirm or refute a diagnosis of developmental delay identified on PARCA-r. Also, on a practical note, the current national database (Badgernet) does not have space for PARCA-R scores in 2 year follow up category- is the committee planning to undertake that change in Badger database nationally?	Thank you for your comment. The aim of this guideline is to ensure all preterm babies receive appropriate developmental follow-up, and as such we have only recommended the minimum requirement. Units who are already exceeding this standard are welcome to continue providing the excellent services they may have already developed locally. However, PARCA-R is still recommended to be used by every unit for several reasons, mainly to ensure parental input into the 2 year assessment and to collect national audit data for quality improvement purposes. The committee carefully considered the available evidence as well as the committee's clinical and parental experience and concluded that PARCA-R is a suitable tool to be used as a minimum developmental assessment tool for children enrolled in the enhanced support and surveillance. Evidence shows that PARCA-R corresponds well with a standardised developmental assessment (Bayley). The cut-off for moderate to severe cognitive and language delay recommended by the committee is a score of less than 49. This is based on a previous validation study among a population similar to the population in the enhanced support and surveillance. The 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects such as gross or fine motor development. If concerns arise, the child should be referred to the local pathway for further assessment. The content of this further assessment is up to the local providers. Lastly, the national neonatal database will be amended to incorporate the PARCA-R scores.
British Association of Perinatal Medicine	Short	14	9	See comments below re choice of PARCA-R	Thank you for your comment. Please see response about the choice of PARCA-R.
British Association of Perinatal Medicine	Short	15	10	This guideline recommends to provide a developmental assessment at 4 years for all children born before 28+0 weeks' gestation, however the current neonatal practice is to follow these babies for 2 years. The guideline should clarify as to who is accountable for SDQ and WPPSI assessments- should this be arranged by community paediatricians or by the neonatal team or by the local authority?	Thank you for your comment. The recommendations state that the enhanced support and surveillance up to 4 years of age for all children born before 28+0 weeks' gestation should be provided by the neonatal service working together with local health services. The recommendations also outline the core members of the multidisciplinary team delivering this support and surveillance. At the 4-year assessment, an educational or clinical psychologist and a paediatrician with expertise in neurodevelopment should be included in the core team and they should have access to other relevant professionals as needed.
British Association of Perinatal Medicine	Short	16	22	The guideline suggests that developmental surveillance should be monitored by checking adherence to the recommendations in this guideline, including follow-up rates and outcomes- but does not define what outcomes mean in each category.	Thank you for your comment. The outcomes to be recorded are list in the neonatal audit section of the guideline.
British Association of Perinatal Medicine	Short	17	13-16	Add in Speech and Language Therapist as 1 of the MDT in the follow up to 2 years	Thank you for your comment. The committee has revised the recommendation and added speech and language therapist to the core multidisciplinary team delivering the assessment at 2 years corrected age.
British Association of Perinatal Medicine	Short	17	13-16	Welcome multidisciplinary approach of input of Physiotherapist/OT. Concern re. Implementation of this in areas where Physio/OT services are extremely stretched.	Thank you for your comment. The provision of required occupational therapy and physiotherapy services will be addressed by local commissioning arrangements.

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British Association of Perinatal Medicine	Short	17	17-19	Clinical Psychologist/Educational psychologists also in short supply in all areas therefor seems impractical to involve them in every assessment of babies less than 28 weeks gestation	Thank you for your comment. We hope the guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of staff to carry out this assessment.
British Association of Perinatal Medicine	Short	18	3	The guideline suggests that 4 year outcomes should be included in neonatal audit and entered in National Neonatal Research Database- are they implying the Badgernet database (which does not currently have a 4 year follow up slot) or is there a new national research database being created?	Thank you for your comment. It is anticipated that the National Neonatal Research Database will be updated to allow input of 4 year data (via Badgernet or another platform).
British Association of Perinatal Medicine	Short	19	3	The guideline recommends to record routine educational measures at key stage 2 on an operational delivery network-wide basis, to allow educational outcomes at 11 years to be linked to neonatal information- Does not state how to achieve that practically.	Thank you for your comment. The recording of routine educational measures at key stage 2 will require implementation of a shared identifier (such as the NHS number) to allow this to be linked to neonatal information. Implementation of this unique identifier is not within the remit of this guideline.
British Association of Perinatal Medicine	Short	24	1-27	Reccs.for Research As both ASQ-3 and PARCA-R need further research into predictive accuracy why not include The Schedule of Growing Skills as well? This test is currently widely used in follow up of children and young people born pre-term and includes elements of observation as well as parental report.	Thank you for your comment. The Schedule of Growing Skills was not included in the evidence review because it is not parent-completed, and therefore as the evidence for its use was not assessed, no evidence gap was identified, and therefore no research recommendation was made.
Child Growth Foundation	Full	General	General	There is no mention of growth monitoring in this guideline. We consider weight and height monitoring to be important in the successful follow-up of preterm babies. We would like to see weight and height measurement included in the developmental assessments proposed at each stage of the follow-up.	Thank you for your comment. We have added the measurement of length/height, weight and head circumference to the checks to be carried out at each developmental visit.
Child Growth Foundation	Full	General	General	There is no mention of IUGR as a risk factor for preterm birth. We know of many babies who were delivered preterm due to IUGR detected by ultrasound. These babies were not born spontaneously and yet they are still preterm. Specifically, with IUGR babies, closer growth monitoring is required.	Thank you for your comment. We did not cover risk factors for preterm birth in this guideline. However, we did look at risk factors for developmental problems and disorders among children born preterm. One of the risk factors of interest was being born small-for-gestational-age. Growth and nutrition, although important, was not in focus in this guideline and is covered in the NICE guideline on Faltering growth also covers children born preterm and is expected to be published in October 2017.
College of Occupational Therapists	Short	3	2	1.1 Risk and Prevalence of developmental problems and disorders – The COT Neonatal Forum is concerned that there is not a section addressing problems with **sensory processing** and **sensory modulation**. Children born prematurely are at risk of atypical sensory development. This would also link in with the outcomes for feeding, ASD and educational attainment.	Thank you for your comment. We agree that atypical sensory development is an important outcome to consider. Sensory sensitivity and sensory difficulties were outcomes of interest for this guideline, however, no evidence on the risk and prevalence of these outcomes in the preterm population was found according to the inclusion criteria set in the review protocols. Due to the lack of evidence, the guideline committee did not make any recommendations in relation to these outcomes.
College of Occupational Therapists	Short	8	2	1.1.19 – Could *Executive function problems* be listed closer to 1.1.6 *Intellectual disability* and 1.17 *Special educational needs* and *Educational attainment*? It seems to be out of place here with the hearing and vision problems and naturally fits with the cognitive impairment sections.	Thank you for your comment. The order of the developmental problems and disorders have been amended as you suggested.
College of Occupational Therapists	Short	9	4	1.2.4 – The emphasis on the impact of a parent's mental health on development needs to be strengthened. We would suggest modifying this point to state: 1.2.4 Recognise the significant potential impact on parents of having a preterm baby and provide emotional and psychological support as needed to parents or carers. Ref: Pizur-Barnekow K, Erickson S (2011) Perinatal Posttraumatic Stress Disorder: Implications for Occupational Therapy in Early Intervention Practice, *Occupational Therapy in Mental Health, 27:2,* 126-139.	Thank you for your comment. We have strengthened the wording of this recommendation so it now reads: 'Provide emotional and psychological support as needed to parents or carers of preterm babies, recognising the significant potential impact of having a preterm baby on all the family.'
College of Occupational Therapists	Short	12	11	1.3.6 –The guideline recommends a minimum of two face to face follow up visits in the first two years of life and developmental assessment at two years (corrected age). We are concerned about the risk of missing diagnosis of neurological conditions in	Thank you for your comment. We have changed the recommendation to say that there should be a minimum of two developmental surveillance appointments in the first year of life, first between 3 to 5 months, and second by 12 months.

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				the first year. A minimum of two developmental surveillance appointments **in the first year** would ensure early diagnosis and treatment for this high risk population.	
College of Occupational Therapists	short	13	19	1.3.8 – We feel that there needs to be an additional point when checking for developmental problems and disorders which relates to finding out about concerns with the young child's daily activities (e.g. play, bathtime, mealtime, dressing, going out with parents/carers). Checking for impairments only and assuming a direct relationship to what the young child is able to do, can be misleading and result in inappropriate support plans, summarised by Humphry (2002): *Intervention models that explain acquisition of skills in daily activities in terms of changing a performance component, such as sensory integration or fine motor abilities, are of concern because evidence suggests that cognition, motor, sensory systems, and emotion develop and operate simultaneously, so meaningful separation is questionable.* *(Diamond 2000; Magnusson 2000; Thelen 1995).* *Furthermore, suggesting internal change as the causal factor underlying development of occupation is not consistent with the conceptualization of occupation as emerging from person–environment interactions (Law et al 2001).* *(Humphry 2002, p.172)* References: Diamond A (2000) Close interrelation of motor development and cognitive development and of the cerebellum and pre-frontal cortex. *Child Development, 71,* 44-56. Humphry R (2002) Young children's occupations: Explicating the dynamics of developmental processes. *American Journal of Occupational Therapy, 56,* 171–179. Law M, Missiuna C, Pollock N, Stewart D (2001) Foundations for occupational therapy practice with children. In: Case-Smith J (Ed.) *Occupational therapy for children* (4th ed). St. Louis, MO: Mosby. pp. 39–70. Magnusson D (2000) The individual as the organizing principle. In: Bergman LR, Cairns RB, Nilsson L, Nystedt L (Eds.) *Developmental science and the holistic approach* Mahwah, NJ: Erlbaum. pp. 33–47. Thelen E (1995) Motor development: a new synthesis. *American Psychologist, 50*(2), 79–95.	Thank you for your comment. We recognise that the abilities and coping skills of each child can vary regardless of an identified developmental problem or disorder. However, the purpose of developmental follow-up is to identify these developmental problems and disorders in order for the child to be referred to an appropriate care pathway. The disorders and problems listed in recommendation 1.3.8 are evidence-based and known to be more common in children born preterm or in children born preterm with specific risk factors (please see recommendation 1.1). The committee recognises that in addition to these developmental problems and disorders, other concerns, including concerns about daily activities, might arise. Recommendations regarding the assessments in the enhanced support and surveillance outlines that at each visit, 1) parents or carers should be asked about any concerns they might have about the child's development; 2) any concerns that might arise during the clinic visit from parent or carer report or by assessing the child should be assessed and reviewed carefully and possibly referred to further assessment or care; and 3) any concern should be discussed with parents or carers. These might include concerns about the child's daily activities, such as play, bath time, meal time etc. In addition, each child should be assessed using PARCA-R parent-questionnaire at 2 years' corrected age, which includes questions related to daily activities. The references listed are helpful in providing insight to developmental processes of children, however, they were not included in the reviews in this guideline because they are narrative articles or chapters and not original studies. Furthermore, these articles and book chapters are on children in general, whereas, the scope of this guideline is restricted to children who are born preterm.
College of Occupational Therapists	Short	14	9	1.3.11 – We are concerned about recommending the PARCA-R as a minimum developmental assessment at two years. The PARCA-R is a screening tool which relies on parental report. Given that the population is at high risk of developmental problems, it would seem more appropriate to suggest a developmental assessment rather than a screening tool.	Thank you for your comment. The aim of this guideline is to ensure all preterm babies receive appropriate developmental follow-up, and as such we have only recommended the minimum requirement. The committee carefully considered the available evidence as well as the committee's clinical and parental experience and concluded that PARCA-R is a suitable tool to be used as a minimum developmental assessment tool for children enrolled in the enhanced support and surveillance. Evidence shows that PARCA-R corresponds well with a standardised developmental assessment (Bayley). Recommending PARCA-R as the minimum aims to ensure parental input into the 2 year assessment. The 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of

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					the assessment process which will include a full professional assessment which will pick up on other aspects such as gross or fine motor development.
College of Occupational Therapists	Short	17	10	1.4.3 – We feel that ideally the MDT involved in surveillance should have worked on the NICU and be known to the families. There is research to show that parents find it easier to attend appointments when they do not have to tell their story multiple times. Our experience is that our DNA rate is lower and our parents report being more confident if seen after discharge by a therapist or doctor they knew during the child's stay on the NNU.	Thank you for your comment. For the 2 year assessment the team will be comprised of professionals from the neonatal unit and so are likely to be known to the family.
Department of Health	General			I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you.
Heart of England NHS Trust	Short	13 16	1 22	The guideline does not specify what constitutes moderate or severe delay in specific developmental domains listed in 1.3.8 Page 13. This had been very clear in the previously published BAPM document "Classification of health status at 2 years as a perinatal outcome, 2008." Such clarification would allow for measuring outcomes of prematurity in a uniform way across networks for audit, benchmarking and research purposes.	Thank you for your comment. The list provided here is for screening purposes only and if any of the developmental problems or disorders listed are suspected, further investigations would then be necessary to confirm the diagnosis and define severity.
Heart of England NHS Trust	Short	14	9	The recommendation states that what should be used as a minimum but possibly it would be useful to indicate which developmental tests are ideal or best suited. Also, on a practical note, the current national neonatal database should then be redesigned to accommodate PARCA-R scores in 2 year follow up category.	Thank you for your comment. The aim of this guideline is to ensure all preterm babies receive appropriate developmental follow-up, and as such we have only recommended the minimum requirement. Units who are already exceeding this standard are welcome to continue providing the excellent services they may have already developed locally. The national neonatal database will be amended to incorporate the PARCA-R scores.
Heart of England NHS Trust	Short	18	3	Just wished to clarify if the National Neonatal Research Database same as the Badgernet database? It does not currently have an option for data on 4 year follow up or is there a new national research database being created?	Thank you for your comment. It is anticipated that the National Neonatal Research Database will be updated to allow input of 4 year data (via Badgernet or another platform).
Homerton University Hospital NHS Foundation Trust	Full	General	General	There are a lot of helpful resources and detail in this document. However its current format is not conducive to wide reading amongst clinicians.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate.
Homerton University Hospital NHS Foundation Trust	Full	529	General: There is a need for information and support around feeding	Feeding problems and the need for feeding support is mentioned in the guidelines, however SLT/ dieticians are not mentioned as a core member of the developmental surveillance group. Preterm infants are at risk of feeding difficulties post discharge from the neonatal unit, *Samara M, Johnson S, Lamberts K, Marlow N, Wole D (2009) Eating Problems at age 6 in a whole population sample of extremely preterm children. Developmental Medicine and Child Neurology. DOI 10.1111/j.1469-8749.2009.03512.x* Feeding problems have a significant impact on children born preterm and on family levels of stress and anxiety. Access to a specialist speech and language therapist and dietician with knowledge about preterm and infant feeding and nutrition would provide families the screening and monitoring of early feeding/ nutrition problems and enable practitioners to provide early preventative support.	Thank you for your comment. A speech and language therapist has been added to the core group as the committee agreed that their involvement was likely to be beneficial with feeding issues, and access to a dietitian is also recommended, where required. The reference mentioned was included in the reviews on risk of developmental problems and prevalence of developmental problems (see section 4.2 and 4.4 in the full guideline).
Homerton University Hospital NHS Foundation Trust	Full	530	map	Question 2: These maps are useful for consideration but to fully implement will have cost implication for most services eg 'Support from neonatal transitional care team at home'	Thanks for your comment. These maps should not be interpreted as recommendations. They are 'theme maps', a tool used in evidence reviews of qualitative studies to show the key themes that have been identified in the review.

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Homerton University Hospital NHS Foundation Trust	Full	556	37	It is identified that mothers benefited from access to dietician to support confidence with caring for their infants. We believe that the dietician provides important early support for families as part of developmental follow up, monitoring growth and nutrition. We believe that dieticians should be named in the core group involved in developmental surveillance.	Thank you for your comment. A speech and language therapist has been added to the core group as the committee agreed that their involvement was likely to be beneficial with feeding issues, and access to a dietitian is also recommended, where required.
Homerton University Hospital NHS Foundation Trust	Full	557	13-15	Question 3: We thoroughly agree with this statement and have recently included a psychologist for parental support on NICU and for transition to the community, who has worked with a number of families to reduce stress and anxiety and would welcome this recommendation in the guidelines.	Thank you for your comment, we are pleased to hear that you welcome the recommendation.
Homerton University Hospital NHS Foundation Trust	Full	558	32-38	The guidelines identify the impact of feeding difficulties on growth and development. However, the importance of nutrition and nutritional support is not mentioned in the guidelines. Feeding and growth remains of primary concern to many families post discharge from the neonatal unit *(Pridham K Sax R, and Limbo R (2004) Feeding issues for mothers of very low birth wieght, premature infants through their first year. Journal of Perinatal Neonatal Nursing 18 (2) 161-169)* Specific comorbidities such as lower gestation age and birth weight for gestation age, CLD, NEC requiring surgery, sepsis place infants more at risk of feeding difficulties both on the neonatal unit and post discharge. Extremely preterm children are at risk of continued feeding difficulties up to and beyond 30 months of age, placing them at risk of growth difficulties including lower mean height and weight BMI, lower head circumference than other children *(Wood NS, Costeloe K, Gibson AT, Hennessy EM, Marlow N, Wilkinson AR for the EPICure Study group. (2003) The EPICure Study growth and associated problems in children born at 25 weeks of gestation age or less. Archives of Disease and Childhood Fetal Neonatal Edition 88 F492-F500* Babies with CLD are at risk of continued difficulties with feeding post discharge from the neonatal unit including difficulties with vomiting, aversive behaviors and the need for ongoing enteral feeding *Martin M and Shaw NJ (1997) Feeding Problems in infants and young children with chronic lung disease. Journal of Human Nutrition and Dietetics 10 271-275.* We believe there is a need for greater emphasis on nutritional/feeding support as part of the enhanced developmental surveillance for preterm infants.	Thank you for your comment. The committee agree that feeding is essential to development but the scope of this guideline relates to developmental follow-up and it is therefore not possible to cover in detail all other aspects of ongoing inpatient neonatal care and care after discharge. The guideline does however recommend information and support be provided to parents regarding managing feeding, and recommends the provision of feeding support after discharge. The core group carrying out enhanced developmental surveillance has also been amended to include a speech and language therapist and access to a dietitian is also recommended, where required.
Homerton University Hospital NHS Foundation Trust	Full	616 603 630	37-39 34-36 37-38	The recommendation of surveillance to 4 years is welcomed. The use of WPPSI would require additional training- most assessments in our centre at this age use the new version of Griffiths which can be used at both 2 years and 4 years and is a familiar and frequently used test clinically. The clinical psychologists would not have capacity to take on surveillance using WPPSI, (the service has high levels of trainees and therefore turnover, making training costs in WPPSI a significant factor) – and the pathway and responsibilities for involvement by educational psychologists if required, managed by a different organisation, would need to be delineated. Lack of available clinical psychologist may also render WPPSI unsuitable.	Thank you for your comment. We have now amended the guideline to state: 'include a standardised test to assess IQ, for example the Wechsler Preschool and Primary Scales of Intelligence 4th Edition (WPPSI) test, including subscales for verbal comprehension, visual spatial skills, fluid reasoning, working memory and processing speed.' This therefore allows organisations to choose which test they use to obtain a measure of IQ. However, we hope that implementation of this guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of additional clinical or educational psychologists.
Homerton University Hospital NHS Foundation Trust	Full	618 589	32-39: challenge to imple	Question 2: Use of PARCA-r in all cases would need an administrator to organise distribution of tests/time of phone calls to be made, with appointment/phone call for feedback. The neonatal follow up team develop a relationship with families and would be most appropriate person to feedback about the assessment, even a normal result.	Thank you for your comment. We recognise that some additional administrative resources might be needed but these were not deemed to be considerable overall.

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		589	mentation 8-20 14	Our centre has a significant number of non-english speaking families who would not be able to access this assessment. Although 'scoring of PARCA-R is considered easy and relatively quick to do', initial training to understand and implement correctly would be required, especially until expertise is established locally. If the service is already using a formal assessment, it seems a backward step to introduce a screening tool that may or may not require a formal assessment as a result. Particularly as this would likely delay any required formal assessment beyond 2 years corrected if PARCA-R cannot be performed before 22 months. If this scenario is in fact covered by the use of PARCA-R 'as a minimum' it would be helpful for that to be explicit.	We agree that neonatal service has likely developed a relationship with the families, and it is their responsibility to organise the enhanced support and surveillance, including the face to face appointments. We recognise the challenge of using this tool among non-English speaking families, however, the committee felt that parental or carer input and involvement is essential for developmental assessment and there is a potential language barrier with any assessment involving parents or carers. Furthermore, PARCA-R can be administered with a help of an interpreter. If administering PARCA-R is not possible, an alternative parent-questionnaire with appropriate translation could be used. We did not consider there to be major training implications in relation to PARCA-R because scoring of PARCA-R is indeed simple, with one simple cut-off point indicating moderate to severe delay in cognition and language development. When concerns arise or a developmental problem or disorder is identified at any stage in the enhanced support and surveillance, the child should be referred to the appropriate local pathway for further assessment. What this contains is up to the local providers. Units who are already exceeding the minimum standard set in the recommendations are welcome to continue providing the excellent services they may have already developed locally.
Homerton University Hospital NHS Foundation Trust	Full	618	34-39	For services that currently use face-to-face assessments such as Bayley or Griffiths at 2 years, moving to PARCA-R may increase cost as those identified as a concern would then need formal assessment, and those with mild-moderate delay are likely to be missed and picked up later when intervention will have been delayed. This would therefore lead to additional testing for some children and possible delay in intervention for others. However the PARCA-r may be a useful addition for selected children eg those who cannot get to clinic/DNA. Especially when identified in advance.	Thank you for your comment. PARCA-R only forms part of the assessment at 2 years and is recommended as a minimum but units which already conduct other tests can continue to use these. The 2 year assessment will include a full professional face-to-face assessment which will pick up on other aspects such as mild developmental delay or motor development (as well as safeguarding and other concerns). Recommending PARCA-R as the minimum aims to maximise the follow-up of these children and ensure parental input into the 2 year assessment.
Homerton University Hospital NHS Foundation Trust	Full	628	13-15	Question 2: Whilst the benefits of this are understood, clarity regarding expectation would be useful eg nurse/administrator/medical staff? This may increase workload for current community discharge services	Thank you for your comment. The committee do not think that having a single point of contact at the neonatal unit will increase workload for the community discharge service.
Homerton University Hospital NHS Foundation Trust	Full	628	12	Feeding problems are identified as an ongoing risk factor for children born prematurely. Children are at risk of persistent oral motor difficulties, difficulties with progression of oral feeding and risk of aspiration. *(Mathisen B, Worrall L, O'Callaghan MO, Wall C, and Shepherd RW (2000) Feeding problems and dysphagia in 6 months old extremely low birth weight infants. Advances in Speech Language Pathology 2 9-17.)* Speech and language therapists are key in assessing risks during feeding and supporting safe and effective feeding both in the neonatal unit and community following discharge from hospital. We believe that having a speech and language therapist as part of the core team for developmental surveillance would allow therapists to provide families with support and advice about managing feeding at home and provide preventative support for feeding development to manage some of these difficulties and improve feeding outcomes for preterm infants	Thank you for your comment. The committee has revised the recommendation and added speech and language therapist to the core multidisciplinary team delivering the assessment at 2 years corrected age.

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Homerton University Hospital NHS Foundation Trust	Full	628	26	Persistent feeding problems are identified as an indicator of possible CP. A speech and language therapist would have a key role in identification of feeding and swallowing difficulties and managing feeding for children with CP. We believe a speech and language therapist would have a key role in monitoring and assessing for feeding difficulties as part of the core team.	Thank you for your comment. The committee has revised the recommendation and added speech and language therapist to the core multidisciplinary team delivering the assessment at 2 years corrected age.
Homerton University Hospital NHS Foundation Trust	Full	628	36	The PARCA- R is identified as a screen of cognition and communication abilities for preterm children in enhanced developmental surveillance. Children born preterm are at increased risk of ongoing speech, language and communication needs (SLCN) including lower receptive and expressive language skills compared with term age peers (*Van Noort-van der Spek I, Franken JP, Weisglas-Kuperus N (2012)* ***Language functions in preterm-born children: A systematic review and meta-analysis.*** *Pediatrics Volume 129 Number 4 745-754.)* We query whether there is a need for a more comprehensive assessment of communication ability at the 2 year follow up appointment. Communication is an important skill for all children, and early identification of SLCN can promote better outcomes through access to early intervention services. We believe that there is a role for a specialist speech and language therapist to support early identification of specific areas difficulty and providing early access to communication support to improve outcomes for these children.	Thank you for your comment. We agree that speech, language and communication needs is a very important developmental area to consider. The PARCA-R tool includes an assessment of language and we have amended the recommendations to include a speech and language therapist as part of the core multidisciplinary team at the 2-year follow-up to ensure that speech, language and communication needs are assessed.
Homerton University Hospital NHS Foundation Trust	Full	630	33	The WPSSI is identified as the recommended assessment tool for the 4 year developmental appointment for the high risk preterm population. Given that the guidelines identify SLCN as a risk for this population, we believe that it would be important to have a specialist speech and language therapist as part of this assessment, as well as a more comprehensive assessment of communication skills. Children at age 4 may be due to start Reception in the next academic year. Evidence suggests that language difficulties at Reception age are a predictor of later language abilities. For example- • vocabulary at 5 years is a powerful predictor of GCSE achievement (Cunningham and Stanovich, 1997) • 'Children who did not achieve the expected standard of early language and communication at five were found to be over four times more likely to have below Level 4 reading at 11 than those who did.' Save the Children (2016) We believe that there is a need for the speech, language and communication skills of preterm children to be assessed and monitored more closely as part of the developmental follow up, by a communication specialist, so that coordinated and timely support can be provided.	Thank you for your comment. The Wechsler Preschool and Primary Scales of Intelligence (WPPSI) is included as an example of the minimum requirement but an alternative test which delivers a measure of IQ could be used, and the wording of the guideline has been amended to reflect this. The committee hope that the guideline will encourage local commissioning arrangements to include the provision of additional clinical psychologists to reduce variability in practice and provide a minimum standard for developmental follow-up of preterm babies. The WPPSI (or alternative if used) will include an assessment of verbal comprehension.
Homerton University Hospital NHS Foundation Trust	Full	631	6-19	We welcome these principles for enhanced support and surveillance.	Thank you for your comment.
Homerton University Hospital NHS Foundation Trust	Full	631	38-40	Developmental assessment at 4- no SLCN assessment	Thank you for your comment. There is no speech and language therapist involvement in the 4 year assessment but parental concerns will be sought and the Wechsler Preschool and Primary Scales of Intelligence (or alternative if used) includes verbal skills and an assessment of verbal comprehension.

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Homerton University Hospital NHS Foundation Trust	Full Appendix	490 618 605 603	3-4 22 table 59 28-32	'Current practice' assumes a clinical psychologist administers the test at 2 years. In the services of which we are aware, where there is a dedicated follow up programme, the neonatologist/community paediatrician/OT administer the two year assessment test and in other services a neonatal doctor administers a screening test and refers on if necessary. We are not aware of the involvement of a clinical psychologist for 2 year assessment in any current service. This would therefore affect the cost analysis of the enhanced programme	Thank you for your comment and particular interest in the cost analysis. In response to the stakeholder comments, the assumption around the personnel involved in the assessment at two years has been changed. It has now been assumed that the follow-up at two years would be the same in current practice and recommended practice (consisting of a neonatologist or paediatrician with or without an OT). As such, the cost analysis at two years was no longer considered necessary as there were no differences to compare in the analysis. Therefore the cost analysis at two years has been removed.
Homerton University Hospital NHS Foundation Trust	Short	15	1-7	Question 3: we developed locally an insert for the Child Health Record (red book) to be given to parents on discharge at 2 years, to highlight that despite being discharged, difficulties with development can appear at a later age and to encourage discussion of concerns with GP/HV/Nursery if they arise. This could be adapted to include Healthy Child Programme and assessment at 4 years.	Thank you for your comment. We agree that this is a good idea.
Homerton University Hospital NHS Foundation Trust	Short	19	3-6	This would be extremely useful but how, where and by whom?	Thank you for your comment. The recording of routine educational measures at key stage 2 will require implementation of a shared identifier (such as the NHS number) to allow this to be linked to neonatal information. Implementation of this unique identifier is not within the remit of this guideline.
King's College Hospital NHS Foundation Trust	Full	General	General	The whole document was extremely long and voluminous .It had too many repetitions. It felt a bit overwhelming reading it and clinicians will not have the time to read it .	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate. Future NICE guidance will no longer be producing a full version of the guideline. The recommendations and evidence will be broken down into smaller sections and presented in a more concise and user friendly manner. The time at which this guideline was developed meant this was produced under the old longer style format.
King's College Hospital NHS Foundation Trust	Full	General	General	There were repetitions and duplications of lists of risk factors and this needs to be more comprehensive.	Thank you for your comment. The risk factors were examined separately for each developmental outcome, therefore, they are listed separately for each outcome depending on what the evidence showed as well as what evidence was available. The specific risk factors that were looked at in relation to the developmental outcomes were chosen by the committee according to their expertise and are listed in the review protocols for Risk of developmental problems and Risk of developmental disorders in Appendix D.
King's College Hospital NHS Foundation Trust	Full	General	General	The scope has included a wide age range , this needs to be up to 4 years of age corrected and not up to 18 years	Thank you for your comment. The guideline covers evidence of developmental problems and disorders in young people up to the age of 18 years, although defined enhanced developmental assessments are only recommended up to the age of 4 years. A further recommendation has been added with regard to presentation in school.
King's College Hospital NHS Foundation Trust	Full	2	1.2 line 1	Algorithm- PARCA- R for 2 year old- concerns re: PARCA- R being the sole assessment for this age group as not age standardised and put the non- English speaking families at a disadvantage PARCA-R may not pick up the cognitive problems and is research based and subjective. The Bayley III, SOGS and Griffiths 3 is a better and more robust assessment tool	Thank you for your comment. The aim of this guideline is to ensure all preterm babies receive appropriate developmental follow-up, and as such we have only recommended the minimum requirement. However, the PARCA-R is not the sole assessment at 2 years of age, The 2 year assessment will be done face to face so safeguarding and other concerns such as gross or fine motor development will be assessed. The committee carefully considered the available evidence as well as the committee's clinical and parental experience and concluded that PARCA-R is a suitable tool to be used as a minimum to assess cognition and language

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					delay in children born preterm enrolled in the enhanced support and surveillance. Evidence shows that PARCA-R corresponds well with a standardised developmental assessment (Bayley). We recognise the challenge of using this tool among non-English speaking families, however, the committee felt that parental or carer input and involvement is essential for developmental assessment and there is a potential language barrier with any assessment involving parents or carers. Furthermore, PARCA-R can be administered with a help of an interpreter. If administering PARCA-R is not possible, an alternative parent-questionnaire with appropriate translation could be used. Recommending PARCA-R as the minimum aims to ensure parental input into the 2 year assessment. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects such as gross or fine motor development.
King's College Hospital NHS Foundation Trust	Full	8	General	There are not the facilities or resources in most units to have an educational psychologist to carry out the WPPSI	Thank you for your comment. The Wechsler Preschool and Primary Scales of Intelligence is included as an example of the minimum requirement but an alternative test which delivers a measure of IQ could be used, and the wording of the guideline has been amended to reflect this. The committee hope that the guideline will encourage local commissioning arrangements to include the provision of additional clinical psychologists to reduce variability in practice and provide a minimum standard for developmental follow-up of preterm babies.
King's College Hospital NHS Foundation Trust	Short	11	general	Need to clarify what "enhanced developmental surveillance " entails and who is going to be doing this	Thank you for your comment. The details of the enhanced developmental surveillance program and the multidisciplinary teams involved in delivering it is provided as part of the recommendations
King's College Hospital NHS Foundation Trust	Short	16	General	Need to clarify who is in the multidisciplinary team- who should be doing what and funding streams for this	Thank you for your comment. We have listed who should be core and non-core members of the multidisciplinary teams. The funding and provision of these teams will be determined by local commissioning arrangements.
King's College Hospital NHS Foundation Trust	Short	18	General	Audit- are the 4 year outcomes going to be linked to Badger and who is responsible for inputting this information	Thank you for your comment. It is anticipated that the National Neonatal Research Database will be updated to allow input of 4 year data (via Badgernet or another platform).It will be a local decision who takes responsibility for inputting this information.
Neonatal Critical Care Clinical Reference Group (CRG)	Short	General	General	The risks and prevalence of developmental problems and disorders are described comprehensively	Thank you for your comment.
Neonatal Critical Care Clinical Reference Group (CRG)	Short	General	General	The information and support for parents and carers of all preterm babies is described in good detail, including recommending use of the Healthy Child Programme	Thank you for your comment.
Neonatal Critical Care Clinical Reference Group (CRG)	Short	General	General	The criteria for enhanced developmental support and surveillance are well defined and achievable. Although this guideline concerns preterm babies, the criteria described for babies between 30^{+0} and 36^{+6} weeks gestation at birth are applicable to babies born after 36^{+6} weeks gestation and this should be mentioned as follow-up programmes are not usually exclusively provided for preterm babies.	Thank you for your comment. We recognise that some children born at term are at a risk of developmental problems and disorders and might require developmental follow-up. However, children born at term are not in the scope of this guideline and the enhanced follow-up programme recommended in this guideline was developed for the defined children born preterm only.
Neonatal Critical Care Clinical Reference Group (CRG)	Short	General	General	Documentation of whether the developmental assessment at 2 years (corrected age) has occurred (as well as outcomes described) should be recorded on Badgernet and linked to the National Neonatal Research Database. Recommendations as to which provider should take responsibility for recording of this need to be made clear in the guideline as confusion regarding this is currently a problem leading to under-recording of the 2 year developmental assessment. The links between Badgernet and the National Neonatal Research Database for this purpose need to be described briefly in the Short and Full version of the guideline.	Thank you for your comment. We agree, and the results of the 2 year assessment will be recorded via Badgernet (or other compatible recording systems used by units) and linked to the National Neonatal Research Database (NNRD). This will be done by the neonatal service who carry out this assessment. Providing specific details of the Badgernet and NNRD links is not within the remit of this guideline as other platforms may be used to feed into the NNRD.

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Neonatal Critical Care Clinical Reference Group (CRG)	Short	14	9	Recommendation to use the PARCA-R as a minimum for the 2 year developmental assessment is welcomed	Thank you for your comment.
Neonatal Critical Care Clinical Reference Group (CRG)	Short	15	10	The recommendation to provide a developmental assessment at 4 years for all children born before 28^{+0} weeks is welcomed but there needs to be careful consideration regarding the cost and funding of this.	Thank you for your comment. We agree that the developmental assessment at 4 years is important. The committee were aware of the potential costs associated with the assessment. Indeed, a cost impact analysis was conducted that demonstrated the likely cost. In the analysis, it was estimated that the cost of implementing the recommendation at four years was £766,426 per year. This falls below the figure of £1 million per year which was deemed to constitute a significant impact according to NICE's resource impact policy. The committee deemed that the costs of the assessment were warranted because of the higher risk associated with children born before 28+0 weeks. Therefore, there is a greater potential to detect problems or disorders in this high risk group. It is hoped that by detecting these problems earlier, it will be possible to better manage them and improve QoL in those patients affected.
Neonatal Critical Care Clinical Reference Group (CRG)	Short	23	7	The recommendations for research are well described and welcomed	Thank you for your comment.
Royal College of General Practitioners	Full	General	General	The RCGP welcomes this guidance for the developmental follow up of children and young people born preterm. The guidance appears to focus predominantly on their childhood and should also consider widening the follow up guidance to include long term follow up into transition and adult hood.	Thank you for your comment. The scope of the guideline is up to 18 years of age and includes the role of health and education services up to this age. In particular, the education services would be expected to take a wider role after 4 years.
Royal College of General Practitioners	Short	20	8	The tools should include relevant SNOMED CT clinical terms and identify any missing important terms that need to be requested for the developmental follow up and young people born preterm. In England SNOMED CT must be implemented across primary care settings by April 2018. Systems used by GP service providers must adopt SNOMED CT as the clinical terminology within the system before 1 April 2018. SNOMED CT must be used in place of Read codes before 1 April 2018. Secondary Care, Acute Care, Mental Health, Community systems, Dentistry and other systems used in direct patient care must use SNOMED CT as the clinical terminology, before 1 April 2020. Using common terms across primary and secondary care particularly in referrals and discharge summaries will help ensure the guidance can be monitored at both a local level in General Practice or a hospital but also by the Clinical Practice Research Database CPRD.	Thank you for your comment. We agree that use of SNOMED CT terms across primary and secondary care will be useful but it is not within the remit of this guideline to identify or develop SNOMED CT terms for developmental follow-up.
Royal College of Nursing	General	General	General	This is to inform you that the RCN has no comments to submit to inform on the above draft guideline consultation. Thank you for the opportunity to participate	Thank you.
Royal College of Paediatrics and Child Health		General	General	Our reviewers advised that they were hoping to find reference in relation to: 1. Patients with borderline motor delay/ speech and language delay but late behaviour and educational difficulties. 2. Consistent under performance in educational setting but not severe enough to get a statement or attend special school. Patients like these are not adequately supported as they do not reach the criteria for CAMHS/ education/ learning difficulties. Parents and patients live with difficulties with no specific forum taking accountability to support them.	Thank you for your comments. We have increased the emphasis within the guideline on ensuring these children who present later are followed up and have included a new recommendation to alert health and educational authorities that preterm birth may be a relevant factor in any child presenting in school with academic, mental or behavioural problems or disorders, and that these children should be referred through local pathways. We do not however, think it is feasible to recommend ongoing regular assessments of all babies who were born preterm after the age of 4, or to adjust CAMHS referral thresholds solely on the basis of prematurity, as most will have no developmental problems.

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				The introduction addresses the evolving difficulties in school age and later. If the surveillance and supports is only until 4 years, what happens later on, what is the recommendation for professional that problems are identified earlier. For example could there be a recommendations like: 1. Educational psychologist performing assessments on preterm, annually or 2 yearly amongst the preterm group. 2. CAMHS to change their threshold of accepting referrals for children with prematurity.	
Royal College of Paediatrics and Child Health				Our reviewer also advised that they were expecting from the title of this guidance that it would also be for young people as well but the guidance refers to support/ surveillance up until age of 4 years. The difficulties of young people like: 1. Educational underperformance. 2. Behaviour problems. 3. School drop outs 4. Transition 5. Employment None of above are taken into account. The title of the guidance can be modified to clarify that it is for only for very young children.	Thank you for your comment. The guideline does cover children and young people up to 18 years and we have amended the wording of some of the recommendations relating to school and education services to reflect this. However, the defined enhanced developmental assessments are only recommended up to the age of 4 years.
Royal College of Paediatrics and Child Health	Full	General	General	Our reviewer advised that in their opinion this document is well structured and clear in the recommendations it presents. It states on page one that the guideline is for education services and they feel that as a document it will be a valuable education resource for healthcare professionals and students working with and learning about children and young people born preterm. The reviewers would suggest that given this focus on education, it would be an opportunity to recommend that hospital and community services for the developmental follow-up of children and young people born preterm incorporate into their design specific provision for continuing education of healthcare professionals. This could include clinics structured with protected time for education opportunities and peer review. Protected education time within the workplace setting would help to create opportunities for healthcare professionals and students to gain exposure to children and young people born preterm, for work placed based assessments, and peer review of senior clinicians and allied health professionals. Specific inclusion of this within a NICE guideline would enable departments to argue for additional resources to promote education. Reference: Watling et al. "sometimes the work just needs to be done": socio-cultural influences on direct observation in medical training. Medical Education 2016: 50: 1054-1064	Thank you for your comments. We hope that the guideline will enable departments to argue for additional resources to promote education, but it is not within the scope of the guideline itself to provide detailed information on continuing education of healthcare professionals.
Royal College of Paediatrics and Child Health	Full	General	General	Excellent overall and is warmly welcome.	Thank you for your comment.
Royal College of Paediatrics and Child Health	Full	General	General	The reviewer shared the overarching concern raised by members with respect to how the recommendations will be achievable in the current climate of service resource. Particularly with respect to clinical and educational resource.	Thank you for your comment. We hope the guideline will encourage resource decisions that allow the recommendations to be implemented, which will be addressed by local commissioning arrangements.

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Royal College of Paediatrics and Child Health	Full	General	General	Have Local Authorities been consulted? It is doubtful that they would/could hire more educational psychologists with the current cuts in education budgets – they are already struggling to deliver on statutory EHC assessments due to most educational psychology services being decimated or privatised. As evidenced by the BACD child development team survey, many district services have no clinical psychologists in their multi-disciplinary teams. **Twenty years of research shows UK child development team provision still varies widely for children with disability** CHILD: CARE, HEALTH AND DEVELOPMENT Volume 39, Issue 6, November 2013, Pages: 903–907, J. R. Parr, N. Jolleff, L. Gray, J. Gibbs, J. Williams and H. McConachie **Variable implementation of good practice recommendations for the assessment and management of UK children with neurodisability** CHILD: CARE, HEALTH AND DEVELOPMENT Volume 41, Issue 6, November 2015, Pages: 938–946, L. Gray, J. Gibbs, N. Jolleff, J. Williams, H. McConachie and J. R. Parr The reviewer would like to urge the guideline committee to carefully think this through, whereas the guidance could act as a driver to improve resource; the reality on the ground in most places is that this will not be deliverable.	Thank you for your comment. Local Authorities have not been consulted but the Department for Education was a Stakeholder for this guideline. We hope the guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of additional clinical psychologists. The aim of the guideline is to reduce variability in services and ensure all preterm babies receive a minimum standard of developmental follow-up.
Royal College of Paediatrics and Child Health	Full	4.3	475	Recommendation 7 on ASD; would be helpful if detail on degree of ICH is available for this to guide health professionals and especially parents as the broad use of ICH will include many babies with grade 1 IVH.	Thank you for your comment. The committee revisited the evidence behind the recommendation and changed the wording to "intraventricular haemorrhage". The evidence shows that there is an increased risk of ASD with both grade 1/2 and grade 3/4 IVH.
Royal College of Paediatrics and Child Health	Full	4.3	476	Recommendation 16 on sleep apnoea; in the reviewer's opinion it is rather a weak recommendation to be aware of this; they could not tell from the evidence section how strong or valid the evidence for this was and how has it been addressed in surveillance and monitoring?	Thank you for your comment. Sleep apnoea has now been added to the list of disorders and problems to be considered at each developmental follow-up visit within the enhanced support and surveillance. As stated in the evidence statements, the evidence for this comes from 1 large study (total N almost 400,000, children born preterm n more than 25,000) and the evidence is considered to be of moderate quality. More details of the study and this piece of evidence is provided in the clinical evidence tables in Appendix K.
Royal College of Paediatrics and Child Health	Full	5.2.3	630	Our major concern is about how WWPSI or equivalent is to be delivered for ALL 4 year olds born <28 weeks. It would be amazing for this to be in place, but in reality how will it be delivered? In the Wessex region, for example, there is not anyone to do WPSSI and are confident that no money will be forthcoming to commission educational psychologists to do the work.	Thank you for your comment. We hope the guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of additional clinical or educational psychologists. The aim of the guideline is to reduce variability in services and ensure all preterm babies receive a minimum standard of developmental follow-up.
Royal College of Paediatrics and Child Health	Recs only	General	General	Very thorough job overall, although implementation might prove difficult in these straightened times. The reviewer did feel the tone was rather negative with respect to outcomes, which might adversely affect communication with families. They suggest adding to section 1 some of the good news, such as that for adults born VP/VLBW, self-perceived quality of life is similar to controls. (Saigal S. Functional Outcomes of very premature infants into adulthood. Semin Fetal Neonatal Med 2014:19:25-30, cited in Johnsons, Marlow N. Arch Dis Child 2017;102:103-108	Thank you for your comment. We have included a more positive statement in the guideline stating that 'that the majority of children born preterm will have a good developmental outcome and good quality of life.'
Royal College of Paediatrics and Child Health	Short	1.24	9	It needs to be extended to support provided to siblings who may be providing primary or secondary carer roles but could be excluded due to lack of young carer awareness from discussions such as this.	Thank you for your comment. Where we have used the term 'carers' in this guideline this includes all carers, whether they be young carers, siblings, grandparents, other relatives, friends or paid carers.

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Royal College of Paediatrics and Child Health	Short	1.4	16	The short guidance clearly outlines which services should be involved and the competencies required; and clearly states there needs to be a single contact for families to turn to for support – which is excellent. In different regions there may be different pathways between neonatal teams, child development teams, acute and community paediatric services. The guideline does not need to be explicit about timings of referrals etc: but it would be helpful if there was some kind of statement to make sure that each region needs to have a transparent communication between the services and there is an overt referral pathway. Some children "slip through the net" between neonatal/community and general paediatric services if each service assumes the other will take responsibility.	Thank you for your comment. We agree that each area should have an agreed local pathway and that communication between the services should be transparent but think the pathways and communication links need to be agreed when commissioning services and agreeing on local implementation plans.
Royal College of Paediatrics and Child Health	Short	1.2.3	general	The reviewers support the approach to follow NICE guidelines on patient experience in NHS services with & Us® RCPCH Voice Bank 2016 data being clear that communication that supports information and involvement in decision-making is key. Our members have stated that for good communication for children and young people (i.e. in this context the long-term support of those born pre-term or the support materials provided to siblings or family members) it needs to: Be short Be provided on a number of occasions – giving everything at the beginning in written or verbal form can be overwhelming Be in a variety of methods in order to support family sharing (one leaflet doesn't work for everyone). Be mindful of those with English as a second language (e.g. BSL, Polish, Urdu). Be visual with images that support the explanation not just stock photos to make it "friendly". Be making the best use of technology – email, text, Whatsapp, trust apps, websites, video stories of patients and their family experiences, social networks / chats. Have language that is accessible. Information shared also needs to be backed up with regular opportunities for communication with clinicians and professionals operating as a "single point of contact" that means they can phone or email between appointments with the suggestion to create long term condition passports to support information tracking and sharing and reduce repetition. Is there a definition provided of the age that "young person" relates to where it is not attributed to the feedback from the YP/PC focus groups? Without being overt in the reference to the full age span of infants, children and young people, my concern is that this becomes inconsistent and leaves potential for gaps to appear. In our work it has become clear that we need to refer to infants, children and young people in all cases where it directly relates to the full age range. It has also been noted young people in our work in 2016, that whilst children is the legal definition that is a catch all, young people (age 11+) do not wish to be termed as a "child". It should be noted that the UNCRC is clear that the right for ICYP to involvement in decisions that affect them is across all ages, with article 23 referencing specifically those with disabilities or additional needs and Article 12 for all ICYP to be involved in decisions that affect them.	Thank you for your comments. We agree that communication that supports information and involvement is key and thank you for your suggestions on what this information needs to include and how it should be delivered. This is in accordance with the NICE guideline on NHS experience in NHS services which is cross-referenced from this guideline, and we have include additional detail in other recommendations. The guideline also, as you suggest, recommends, a single point of contact. The definition of infants, children and young people used in most NICE guidelines are from age 1 month to 1 year, >1 year to 10 years, and 11 to 17 years respectively and these terms are used appropriately in this guideline. We agree that it is the right of the child or young person to be involved in decisions that involve them and do not think this right is contradicted in this guideline.
Royal College of Paediatrics and Child Health	Short	1.2.5	9	As per response to 1.2.3 plus additional information shared for young carers.	Thank you for your comment. Where we have used the term 'carers' in this guideline this includes all carers, whether they be young carers, siblings, grandparents, other relatives, friends or paid carers.

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Royal College of Paediatrics and Child Health	Short	1.2.6	9	As per response to 1.2.3.	Thank you for your comment. Please see our response to your comments on 1.2.3.
Royal College of Paediatrics and Child Health	Short	1.3.5	12	We support this recommendation - & Us® RCPCH Voice Bank 2016 evidence can be provided regarding this request from ICYPF	Thank you for your comment and we are pleased you support the range of communication options we have suggested. Thank you for the offer of evidence from &Us. This looks likely a useful resource, but unfortunately has been received too late to be used in this guideline.
Royal College of Paediatrics and Child Health	Short	1.2.7	9	As per response to 1.2.3.	Thank you for your comment. Please see our response to your comments on 1.2.3.
Royal College of Paediatrics and Child Health	Short	1.2.8	9	As per response to 1.2.4.	Thank you for your comment. Please see our response to your comments on 1.2.4.
Royal College of Psychiatrists	Short	17	20	We suggest NICE add the sentence: "The multi-disciplinary professionals should work closely with the Health Visitor and keep the GP informed"	Thank you for your comment. The recommendations already state that information should be shared with the primary and secondary healthcare teams and this includes GPs and Health Visitors.
St George's University Hospitals NHS Foundation Trust	Full	General		This is an enormous guideline and has taken considerable time to read. The short version is an extremely brief outline and does not provide enough detail. We would welcome a more usable, clinically relevant guideline for people working in clinical follow-up that is tailored to their needs and to those of the children that are followed-up.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate.
St George's University Hospitals NHS Foundation Trust	Full	613-618	General	We are very concerned that the enhanced developmental plan at 2 years does not include a robust assessment of cognitive and language skills with an objective, standardised tool such as Bayley 3 scales of infant and toddler development (acknowledged as a gold standard in this guideline). In our experience parents are often poor at judging their child's progress and the use of a self- administered parent questionnaire will not be a satisfactory alternative.	Thank you for your comment. The evidence showed PARCA-R to correspond well with the standardised test (Bayley) to identify moderate to severe cognitive and language delay among the preterm population. It also ensures involvement of the parents in the assessment which the committee considered essential. PARCA-R was therefore considered appropriate as the minimum required tool to be used. Units who are already exceeding the minimum standard set in the recommendations are welcome to continue providing the excellent services they may have already developed locally. Furthermore, the 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects including gross and fine motor development.
St George's University Hospitals NHS Foundation Trust	Full	557-559	17-51 & 1-5	We agree that the discharge process should be robust and that a key point of contact is crucial for supporting families who take preterm children home.	Thank you for your comment.
St George's University Hospitals NHS Foundation Trust	Full	517	20-35	We welcome the emphasis on improving information given to parents whilst there baby is on the NNU.	Thank you for your comment and agreement.
St George's University Hospitals NHS Foundation Trust	Full	605	Table	The economic case for having a four year detailed assessment is based on the assumption that the 2 year assessment involves 4 people – neonatologist/psychologist/nurse/physio or OT. In our practice we use a neonatal paediatrician and a physiotherapist at 2 years. Therefore we would not have the cost saving that is detailed in the guideline to support the 4 year detailed assessment.	Thank you for your comment and particular interest in the cost analysis. Following the stakeholder comments, revisions have been made to the assumptions on the personnel involved in the assessment in current practice. We have now assumed that a neonatologist and OT/physiotherapist would be likely to carry out the assessment at two years in both current and recommended practice. The cost analysis at two years has now been removed as there is no difference in personnel between the two approaches. As you point out, this means that there are no longer cost savings at two years to outweigh the increased costs at four years. However, the cost at four years is thought to be justified by the potential to detect problems or disorders in this high risk group. It is hoped that by detecting these problems earlier, it will be possible to better manage them and improve QoL in those patients affected.

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					Furthermore the cost of implementing the recommendation at four years is estimated to be £766,426 per year. This falls below the figure of £1 million per year which was deemed to constitute a significant impact according to NICE's resource impact policy.
St George's University Hospitals NHS Foundation Trust	Full	616 617	10-51 1-51	1. We agree that a full developmental review at 4 years including behaviour would be very much in the child's best interest in order to inform both family and educational services. However, we do not think that this should be at the expense of a detailed review at 2 years. Unfortunately in our Trust we would be unlikely to get the engagement of our community/developmental paediatricians – they do not have any resources to support the preterm population and as detailed above we would not make any savings from our 2 year assessments.	Thank you for your comment. The cost analysis has been revised in light of the stakeholder comments. While this does mean that the cost increase of the assessment at four years is no longer offset by the cost saving at two years, the committee still think that the review at four years is an appropriate use of resources. It should also be noted that the four year assessment is not intended to come at the expense of a detailed review at two years. The decision made at two years was justified on its own merits.
St George's University Hospitals NHS Foundation Trust	Full	618	28-39	The guideline states that the PARCA-R may not identify mild to moderate disability well. Moderate disability itself is very disabling in a family setting and we have great concern that to miss this at the age of 2 years is not in the child's interest, or in the interest of families. Support and community services with early intervention programmes need to be introduced early to aid the child's development. Even for children with mild disability picked up by the Bayley scales, our practice is to refer on for extra support. We feel that it is essential that moderate and mild disability is picked up at this stage and these need to be done with a robust assessment tool.	Thank you for your comment. Recommending PARCA-R as the minimum aims to maximise the follow-up of these children and ensure parental input into the 2 year assessment. We agree that it is very important to identify and address mild and moderate disability. The 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects such as parental concerns, mild developmental delay or motor development. Furthermore, units who are already exceeding the minimum standard set in the recommendations are welcome to continue providing the excellent services they may have already developed locally.
St George's University Hospitals NHS Foundation Trust	Full	618	28-29	1. By the admission of the guideline itself the PARCA-R is not age standardised and has to be used in a narrow age spectrum of 22-26 months. We have concerns that this is impractical in a clinical setting. Families who do not fill it in during these four months and/or DNA at a clinic will need to have a different sort of assessment. It is therefore not flexible enough for a real life clinical situation compared to a tool that is age standardised. 2. Getting questionnaires filled in and returned is difficult even in a research setting when more resources are available to chase them. We are concerned that lack of return of these questionnaires will likely lead to less data on 2 year outcomes than we presently have, which is about 85% of our patients who come for a Bayley assessment. 3. A parent self-administered questionnaire will be a burden for some parents. We feel that the burden should be taken on by the clinician.	Thank you for your comment. Indeed, PARCA-R is only validated in a relatively narrow timeframe. We hope that if parents and carers are clearly informed about the timeframe and the importance of it, it would not be a huge issue. However, if the assessment is missed within the timeframe, an alternative age-standardised parent questionnaire could be used. We leave it for the clinicians to decide which tool would be most suitable in these cases. We understand the concern about the response rate. The 2-year assessment is a face-to-face assessment to which PARCA-R contributes, and therefore, you could expect at least a similar attendance rate than with Bayley assessment. If parents or carers have not had a chance to fill in and return the questionnaire beforehand, there is a possibility to fill in the questionnaire while in the waiting room. The committee, including the parent and carer members, felt that having a parent questionnaire as part of the assessment ensures the involvement of the parents, which is important from the point of view of the assessor as well as the parent or carer. It also acts as a point of reflection for the parents regarding their child's development which we find important. PARCA-R is quick and easy to administer so we hope that parents and carers would not feel overly burdened by it.
Staffordshire, Shropshire & Black Country Newborn and Maternity Network	Short	general	general	There isn't anything that I can see about the statutory duty to refer to the local authority by health if a child is likely to have a Special educational need or disability to allow for early intervention (SEND code of practice and Children and Families Act)	Thank you for your comment. We recognise that there are statutory duties for organisations under the 'Special educational needs and disability code of practice' but would expect organisations to have separate processes in place to comply with this legislation for all children/young people who interact with their services.

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Staffordshire, Shropshire & Black Country Newborn and Maternity Network	Short	General		It looks as if there would be significant implications for training, cost and resources with no real evidence that this would improve outcomes at all in comparison to our current practice.	Thanks for your comment. The guideline is anticipated to increase costs in some areas but not substantially. According to the NICE resource impact policy, a cost of £1 million per year for a single recommendation would be deemed significant. No single recommendation in the guideline is anticipated to cost more than £1 million per year. In comparison to current practice, it is hoped that the key benefit of the recommendations will lead to the earlier detection of problems and disorders and greater equity. Analysing the effect of earlier detection in terms of outcomes was beyond scope of this guideline.
Staffordshire, Shropshire & Black Country Newborn and Maternity Network	Short	11	4	Cut off at 30+0 weeks means risk of missing developmental problems in other preterm babies as many may have developmental problems without having had abnormal cranial USS etc. There is a false cut off of 36+6 weeks with relation to HIE – Surely follow up for HIE should be the same regardless of gestation?	Thank you for your comment. The committee recognises that some children born between 30+0 and 36+6 weeks' gestation might develop developmental problems and disorders, however, evidence shows that the risk for this is low unless there are risk factors including abnormal cranial ultrasound scan. Recommendation 1.3.2 outlines that children born between 30+0 and 36+6 weeks' gestation without the aforementioned risk factors can be considered for the enhanced developmental support and surveillance if, according to clinical judgment, the child is considered to be at an increased risk of developmental problems and disorders. In addition, all children, regardless of their gestation are enrolled in the national Healthy Child Programme where the child's development is followed. Developmental follow-up for children born at term (later than 36+6 weeks' gestation) is outside of the remit of this guideline which is restricted to children born preterm (before 37 weeks' gestation).
Staffordshire, Shropshire & Black Country Newborn and Maternity Network	Short	14	5	PARCA-R is intended to be completed by parents and returned by post or electronically. It is well known that rate of return for questionnaires carried out in this way is very poor. It will only be completed by motivated parents, so an alternative method would then need to be used in the majority. High risk of inaccurate completion if completed at all – well established that parental reporting is unreliable It only screens for cognitive and language delay No gross or fine motor component and no alternative screen for this suggested as 'more research needed' – Still need to use something in the meantime. No face to face meeting so lost opportunity to pick up safeguarding or other concerns PARCA –R is not widely used currently so would be huge implications for training – cost, time, resources Evidence appears weak that it is much better than ASQ so hard to justify the training needed. I don't think this was accounted for in the cost analysis. PARCA-R is not age-adjusted and can only be administered between 22 and 26 months. An alternative method would be needed outside these times. Any recall would have to use an alternative method as would then be outside the age range. Would administering this be the remit of health visitors? If so, have they been consulted? Health visitors would still be using ASQ for all other children so may lead to confusion NNAP requires level of detail of developmental delay that can be provided by SOGS, Bayley III or Griffiths. PARCA-R would not provide this. The PARCA-R at 2 I don't really know and I can't see from the literature how it compares to the ASQ which the child will already have at this age as part of the	Thank you for your comment. The PARCA-R can be completed by the parents prior to the 2 year assessment visit or in the waiting room, or can be completed with the assistance of a healthcare professional at the visit. It aims to ensure parental input into the 2 year assessment and only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects such as gross or fine motor control. The 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. As the PARCA-R is parent completed with a very simple scoring system it is not anticipated that training will have major implications. If PARCA-R cannot be used then an alternative is required: the recommendation has been amended to allow the use of any other suitable parent-completed questionnaire such as ASQ. The PARCA-R will be administered by the enhanced developmental follow-up team, not by Health Visitors, and some children may be assessed by Health Visitors using the ASQ as well. The National Neonatal Audit Programme (NNAP) will be amended to take into account these recommendations. The evidence shows that the PARCA-R provides greater sensitivity and specificity than ASQ when compared to a reference standard diagnostic test at 2 years. The evidence review did not seek to find evidence comparing PARCA-R directly to ASQ but rather both of these tools to a standardised diagnostic test (such as Bayley). The assessment for each child should be done using a number of methods, not only a parent-questionnaire, ensuring that a thorough assessment including parental views is conducted.

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				healthy child programme. At 2 the child could end up with a whole range of assessments all at once: The ASQ plus in some areas SOGS as part of the healthy child programme plus they may have the integrated 2 years check with education colleagues who use their EYFS so it does seem rather repetitive for the child This would add in PARCA-R and SDQ	
Staffordshire, Shropshire & Black Country Newborn and Maternity Network	Short	14	19	Follow up at 4 years – not clear who would be responsible for this. Suggests clinical or educational psychologist as well as paediatrician but are there resources for any of this? Cut off of 28+0 weeks may miss many who would benefit from additional input.	Thank you for your comment. The assessment at 4 years will be conducted by an educational or clinical psychologist and a paediatrician with expertise in neurodevelopment. We hope the guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of staff to carry out this assessment. The cut-off at 28 weeks is a balance between the need to include as many children as possible, the resources available and the evidence for the increasing risks with decreasing gestational age.
Staffordshire, Shropshire & Black Country Newborn and Maternity Network	Short	15	21	The 4 year assessment recommended i.e. the WPPSI is not carried out by Community Paediatricians. This is an assessment usually carried out by an Educational Psychologist or possibly a clinical psychologist. The Educational Psychologist is unlikely to do this where nursery are not highlighting learning difficulties as they are paid by the local authority to do statutory work. Clinical psychologists would not be generally doing it as part of their workload as they are focusing on children who meet the criteria for CAMHS ie tier 3 with a significant and enduring and mental health condition There would need to be a significant need for a change in commissioning of services to achieve this	Thank you for your comment. We hope the guideline will encourage resource decisions, addressed by local commissioning arrangements that will lead to the employment of staff to carry out this assessment.
Staffordshire, Shropshire & Black Country Newborn and Maternity Network	Short/Full	general	general	This guideline is too long, even the short format is 25 pages.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate. Future NICE guidance will no longer be producing a full version of the guideline. The recommendations and evidence will be broken down into smaller sections and presented in a more concise and user- friendly manner. The time at which this guideline was developed meant this was produced under the old longer style format.
Thames Regional Perinatal Group- Outcomes subgroup	full	general	general	We felt overwhelmed by the amount of information presented and left concerned that an ordinary clinician won't be able to read and take on board the extensive document presented here. We will be commenting on the initial summary of the full version and the short version but the comments should be taken for the full version. On the scope, we feel that the age range is too wide- from birth to 18 years old, but the guideline only covers to 4? How is this relevant to the guideline? The guideline is extremely long and rather vague with significant duplication of information. We think that there is frequent repetition of lists particularly of risk factors which is probably unnecessary. In general, we understand that many stakeholders were involved but primary user involvement is not evident in the end result. The amount of information is too specialised or detailed for clinical use and needs to be simplified for regular use by the clinicians/ therapists actually doing the follow up.	Thank you for your comments. We appreciate that the full version of a NICE guideline is a very large document but this is necessary to ensure that the recommendations are based on a transparent review of the evidence. Future NICE guidance will no longer be producing a full version of the guideline. The recommendations and evidence will be broken down into smaller sections and presented in a more concise and user friendly manner. The time at which this guideline was developed meant this was produced under the old longer style format. The guideline does cover to 18 years and we have amended the wording of some of the recommendations relating to school and education services to reflect this. However, the defined enhanced developmental assessments are only conducted up to the age of 4 years. The list of risk factors are repetitive because we have provided them in terms of outcomes, and a number of different risk factors lead to the same developmental

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					outcomes. The committee agreed that this was the clearest way of presenting the information. The guideline was developed by a multi-disciplinary committee who included professionals and parents who will be the end users for this guideline, and the short version contains the minimum amount of information necessary for implementation. As part of the implementation process a visual pathway of the guideline will be available on the NICE website and we hope this will be useful.
Thames Regional Perinatal Group- Outcomes subgroup	full	7	general	On membership- The extent of this clinical document (more than 800 pages of guideline and more than 800 pages of appendices) and the wideness of the scope made us aware of the likely high input by research members of the panel; whilst their expertise and valuable insight is very much acknowledged, we were concerned that other members with more clinical expertise may have been outweighed.	Thank you for your comment. The guideline committee was composed of a variety of experts in the topic with the vast majority of the committee members being clinical experts. Please see Table 1 in the Full guideline document to see the composition of the committee and each member's role. Lay members' and clinicians' expertise and insight was at the centre of the committee's discussion and decision making throughout the development of this guideline. The rigorous process that NGA and NICE follows when producing these guidelines and the amount of available evidence contributes to the length and depth of these guideline documents.
Thames Regional Perinatal Group- Outcomes subgroup	full	8	general	We are aware of the extent of missed opportunities when systematic and consistent approach is not followed. It worries us that 'checks', 'tailored support' and a 'range of approaches' may be misinterpreted and that potential problems are not identified. We would recommend face-to-face assessments by expert clinicians linked to neonatal units. There is enough research and clinical expertise on the Prechtl Assessment of General Movements at three to four months of life- corrected for prematurity (recommended by the NICE guidance for CP in the less than 25 years) so we would think that it should be recommended in this guideline.	Thank you for your comment. For all children enrolled in the enhanced support and surveillance, we recommend a minimum of two face to face assessment before 1 year of corrected age (this was amended according to stakeholder comments), first between 3 to 5 months and second by 12 months, and a face-to-face assessment at 2 years of corrected age by a multidisciplinary team of experts organised by the neonatal service. Additionally, children born before 28+0 weeks' gestation should receive a face-to-face assessment at 4 years of age. We refer to the NICE guidance on cerebral palsy in children and young people under 25 for assessment of signs of cerebral palsy in the recommendations, therefore the assessments recommended in that guideline are supported.
Thames Regional Perinatal Group- Outcomes subgroup	full	8 618	general	Age 2- We are extremely concerned on the use of telephone PARCA-R as the sole assessment 'at 22-26 months'- this may not be achievable for all children at this age, its not age standardised, is not for non-English speakers, it has a narrow spectrum and may not pick up the mild to moderate cognitive problems that you mentioned in the guideline. We would strongly recommend a more formal and standardised neuro-developmental face-to-face assessment by a trained clinician, (either Bayley III, Griffiths 3, SGS, or other as per clinician's choice). In addition to a formal assessment, We would suggest using the TRPG-2y outcome form to document and report as is already linked with the Badger system in all neonatal units in UK.	Thank you for your comment. The aim of this guideline is to ensure all preterm babies receive appropriate developmental follow-up, and as such we have only recommended the minimum requirement. The committee carefully considered the available evidence as well as the committee's clinical and parental experience and concluded that PARCA-R is a suitable parental tool to be used as a minimum to assess cognition and language delay in children born preterm enrolled in the enhanced support and surveillance. Evidence shows that PARCA-R corresponds well with a standardised developmental assessment (Bayley). We recognise the challenge of using this tool among non-English speaking families, however, the committee felt that parental or carer input and involvement is essential for developmental assessment and there is a potential language barrier with any assessment involving parents or carers. Furthermore, PARCA-R can be administered with a help of an interpreter. Recommending PARCA-R as the minimum aims to ensure parental input into the 2 year assessment. The 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects including gross and fine motor development. The committee considered that the TRPG-2y form which is used to collate data should be updated to allow input of the PARCA-R, and a request will be made to update the National Neonatal Research Database.

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Thames Regional Perinatal Group- Outcomes subgroup	full	8	general	Age 4- We welcome this assessment and would like it to be extended to all high risk groups as described in comment 2. Our main concern is about implementation mainly because of the amount of tests: "SDQ, WPPSI or a suitable alternative and orthoptics" and the potential lack of availability and experience of educational psychologists for testing.	Thank you for your comment. The 4 year assessment will be provided to all preterm babies born before 28 weeks as the evidence showed that this is the group most likely to be at risk of problems affecting educational attainment. There are a number of tests at age 4, and the recommendation has now been amended to include the parentally-completed Strengths and Difficulties Questionnaire (SDQ) and the Ages and Stages Questionnaire (ASQ), as well as the WPPSI and orthoptic screening. These tests address different aspects of developmental follow-up, and allow parent input into the assessment too, and thus provide for a very comprehensive assessment. The tests can be conducted by a clinical psychologist or an educational psychologist, and it is hoped this guideline will encourage commissioning decisions to allow flexibility in the workforce to deliver the 4 year assessment.
Thames Regional Perinatal Group- Outcomes subgroup	full	8,10	general	On the surveillance algorithm, We are concerned that the guideline is missing high-risk neonates. We welcome the thought of considering all preterm babies at increased risk, and would classify as high risk all the less than 32 weeks and all the less than 1500 grams	Thank you for your comment. The scope of this guideline included preterm babies < 37 weeks gestation. Inclusion for the enhanced developmental support and surveillance was based on gestational age rather than birth weight. The guideline committee carefully considered the gestational age cut-offs to enter the enhanced developmental support and surveillance up to 2 years' corrected age and up to 4 years of age by taking into account the evidence on the risk and prevalence of developmental problems and disorders in children born at different gestational ages. In the end, the committee had to consider the balance between cost and yield, bearing in mind that the absolute number of children born preterm increase by increasing gestational age. We recognise that a strict cut-off is always arbitrary. Therefore, children born between 30+0 and 36+6 weeks' gestation are included in the enhanced developmental support and surveillance if they have risk factors listed in the recommendation 1.3.1 or they can be considered for inclusion if they are considered, by clinical judgment, to be at an increased risk of developmental problems and disorders for some other reason. In addition, all children, regardless of gestation age at birth, are enrolled in the national Healthy Child Programme where the child's development is followed.
Thames Regional Perinatal Group- Outcomes subgroup	full	9,10,11,12,13,14,15,16,17,18	general	On recommendations- This section is unnecessarily and extensively duplicated. We are concerned of the significant research bias. We would welcome a user friendlier version for clinicians without so much detail and with more practical issues	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate.
Thames Regional Perinatal Group- Outcomes subgroup	full	604-5	Table 59	On costs of current practice – this current practice include costs for a neonatologist and a psychologist as well as a therapists. The assumption being the psychologist undertakes the formal assessment ie Bayley). We are concerned that this does not reflect current practice. From a recent survey submitted for publication by the TRPG outcomes group, of 110 out of 180 neonatal units in England no one stated psychologists as doing follow up. Removing the clinical psychologist from current practice may make the enhanced surveillance more expensive. The costs of training in PARCA-R and WIPPSI are also not assessed	Thank you for your comment and particular interest in the cost analysis. Thank you also for sharing the survey results. Following the stakeholder comments, revisions have been made to the assumptions on the personnel involved in the assessment in current practice. We have now assumed that a neonatologist and OT/physiotherapist would be likely to carry out the assessment in current and recommended practice. The costs associated with training were discussed and considered when making the recommendations. They were not formally included in the cost analysis because of a lack of data on the likely costs associated with this training.
Thames Regional Perinatal Group- Outcomes subgroup	General	General	General	**Q1 - Which areas will have the biggest impact on practice and be challenging to implement?** *Please say for whom and why*. By providing a structured surveillance programme for high risk children, the most impact will be for parents and their environment Neonatal Units will also feel the impact because specific outcomes are likely to be used for benchmarking.	Thank you for your comments. We agree that this guideline will have a good, positive impact for parents. It aims to also reduce variation in practice between neonatal units (and bench-marking will help this) and also to increase the awareness of developmental problems in preterm babies by community and education services.

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				Community and Education services will see their workload increased, and as parental support is implemented as a consequence of enhanced surveillance.	
Thames Regional Perinatal Group- Outcomes subgroup	General	General	General	**Q2 - Would implementation of any of the draft recommendations have significant cost implications?** Yes, the overall recommendation about surveillance of high risk children from before discharge to 18 years is probably very costly. From discharge to two years- The whole follow up for a high risk baby for the first two years has the same cost of one day of intensive care in the NHS. A recent survey by TRPG-OG about follow up practices in UK showed that most units are already doing this until two, so we don't expect significant changes in terms of costs. Implementing a service for high risk 4 year olds onwards with educational psychologists, referrals, school placements, etc is likely to generate significant expenses with impact on cost to the Community Services and the Education departments.	Thanks for your comment and for highlighting areas where there may be significant cost implications. The recommendations covering high risk children were thought to be justified by the greater potential for detecting problems or disorders in this group. We agree that there is unlikely to be any significant changes in cost as a result of the changes to the assessment at 2 years. The cost of the assessment at four years was estimated in the guideline. It was estimated that the cost of implementing the recommendation at four years was £766,426 per year. This falls below the figure of £1 million per year which was deemed to constitute a significant impact according to NICE's resource impact policy. It should be noted that education department or community services costs were not estimated as part of the analysis. However the committee considered and extensively discussed the impact on these services when agreeing their recommendations
Thames Regional Perinatal Group- Outcomes subgroup	General	General	General	**Q3 - What would help users overcome any challenges?** (*For example, existing practical resources or national initiatives, or examples of good practice.)* NICE guidelines are examples of good practice and help users overcome challenges as long as they provide reasonable outcomes that are achievable within the constraints of the NHS/Education/social departments. Users' sense of ownership by understanding of the importance of the service and involvement with implementation will definitely increase the chance of success.	Thank you for your comments. We believe that the recommendations in this guideline are achievable and hope that users can be fully involved as services implement the recommendations to ensure success.
Thames Regional Perinatal Group- Outcomes subgroup	short	11	general	"enhanced developmental surveillance" please refer to comment 3	Thank you for your comment. Please see response to comment 3
Thames Regional Perinatal Group- Outcomes subgroup	short	13	general	Checking for developmental problems Please refer to comment 3 above	Thank you for your comment. Inclusion for the enhanced developmental support and surveillance was based on gestational age rather than birth weight. The guideline committee carefully considered the gestational age cut-offs to enter the enhanced developmental support and surveillance up to 2 years' corrected age and up to 4 years of age by taking into account the evidence on the risk and prevalence of developmental problems and disorders in children born at different gestational ages. In the end, the committee had to consider the balance between cost and yield, bearing in mind that the absolute number of children born preterm increase by increasing gestational age. We recognise that a strict cut-off is always arbitrary. Therefore, children born between 30+0 and 36+6 weeks' gestation are included in the enhanced developmental support and surveillance if they have risk factors listed in the recommendation 1.3.1 or they can be considered for inclusion if they are considered, by clinical judgment, to be at an increased risk of developmental problems and disorders for some other reason. In addition, all children, regardless of gestation age at birth, are enrolled in the national Healthy Child Programme where the child's development is followed

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Thames Regional Perinatal Group- Outcomes subgroup	short	14	general	Developmental assessment at 2 years- please refer to comment 5 above	Thank you for your comment. The aim of this guideline is to ensure all preterm babies receive appropriate developmental follow-up, and as such we have only recommended the minimum requirement. The committee carefully considered the available evidence as well as the committee's clinical and parental experience and concluded that PARCA-R is a suitable tool to be used as a minimum to assess cognition and language delay in children born preterm enrolled in the enhanced support and surveillance. Evidence shows that PARCA-R corresponds well with a standardised developmental assessment (Bayley). We recognise the challenge of using this tool among non-English speaking families, however, the committee felt that parental or carer input and involvement is essential for developmental assessment and there is a potential language barrier with any assessment involving parents or carers. Furthermore, PARCA-R can be administered with a help of an interpreter. Recommending PARCA-R as the minimum aims to ensure parental input into the 2 year assessment. The 2 year assessment will be done face to face so safeguarding and other concerns can be addressed. PARCA-R only forms part of the assessment process which will include a full professional assessment which will pick up on other aspects including gross and fine motor development. The National Neonatal Research Database will be updated to allow input of PARCA-R data.
Thames Regional Perinatal Group- Outcomes subgroup	short	15	general	Developmental assessment at 4 years Please refer to comment 6	Thank you for your comment. The 4 year assessment will be provided to all preterm babies born before 28 weeks as the evidence showed that this is the group in whom there are most likely to be future educational problems. There are a number of tests at age 4, and the recommendation has now been amended to include the Strengths and Difficulties Questionnaire (SDQ) and the Ages and Stages Questionnaire (ASQ), as well as the WPPSI and orthoptic screening. These tests address different aspects of developmental follow-up, and allow parent input into the assessment too, and thus provide for a very comprehensive assessment. The assessment at four years (including the additional tests) was anticipated to require an assessment by a psychologist and a consultation with a paediatrician. The recommendation was estimated to cost an additional £766,426 per year. This falls below the figure of £1 million per year which was deemed to constitute a significant impact according to NICE's resource impact policy.
Thames Regional Perinatal Group- Outcomes subgroup	short	16	general	On the multidisciplinary team- there is no clarity on funding or on "who should be doing what and who would be responsible for coordination"	Thank you for your comment. The organisation and coordination of the multidisciplinary team is a decision that should be made locally as the committee understand that the configuration of these teams will vary. The funding and provision of these teams will be determined by local commissioning arrangements.
Thames Regional Perinatal Group- Outcomes subgroup	short	18	general	On neonatal audit Data from structured assessments is to be linked to the Neonatal Dataset (Badger) on the 2 year outcomes form already in place Data on the 4 year assessment to be linked to the Neonatal database- important to recommend on the responsible professional for this	Thank you for your comment. It is anticipated that the National Neonatal Research Database will be updated to allow input of 4 year data (via Badgernet or another platform).It will be a local decision who takes responsibility for inputting this information.
Thames Regional Perinatal Group- Outcomes subgroup	short	19	general	On recording educational measures – We would welcome a line for recommending who would the responsible person be to do this and where would the funding be coming from	Thank you for your comment. The choice of responsible person is a local decision, and the funding will be addressed by local commissioning arrangements.
The Multiple Births Foundation (MBF)	Full/Short	General	General	The Multiple Births Foundation is a charity offering professional support to families with multiple births through direct services and providing information and training for health card and allied professionals about their special needs. As the risk of preterm birth is higher, occuring in over 50% of twins births and almost 100% of triplet births, we welcome all the recommendations in this draft guideline.	Thank you for your comment. We appreciate that this is an important issue. However, we consider taking into consideration the difficulties faced by families with twins or tripletsis part of general principles of good practice applying to any contact with the health services, not only developmental follow-up. As this

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				We suggest that consideration is given to making a general statement in both documents about the importance of ensuring that in families with twins or more each child is assessed and treated individually and that appointments and assessments allow time for this. We hear all too often from parents that this is not the case. It may also be helpful to incorporate this into some recommendations as suggested for consideration below. Parents also report that they are at times given conflicting appointments for each of the children so a key worker co-ordinating the follow-up for all the children in a multiple birth family can make an enormous difference. If this could be recommended it would be a great help.	guideline is already very detailed we have not included specific recommendations relating to multiple births.
The Multiple Births Foundation (MBF)	Short	8	20 - 21	We suggest the following addition to the text: "1.2.2 Provide information to parents or carers of preterm babies that is tailored to their individual circumstances, and if twins or triplets for each child ,taking into account: "	Thank you for your comment. We believe that it is part of general principle of good practice to consider individual children, whether singleton, twin or triplet, and it applies to any contact with the health services and is therefore, not specific to this guideline.
The Multiple Births Foundation (MBF)	Short	12	1,2,3	1.3.5 Use a range of approaches when providing enhanced 1 developmental support and tailor the support to take account of 2 individual preferences and needs. If twins or triplets take into account the greater practical difficulties of taking two or more children having advanced developmental support and surveillance to appointments and allow time for each child. Approaches may include	Thank you for your comment. We believe that it is part of general principle of good practice to consider individual children, whether singleton, twin or triplet, and it applies to any contact with the health services and is therefore, not specific to this guideline.
The Royal College of Midwives (RCM)	Short	General		The RCM welcomes the publication of this useful guideline that will support the effective follow up of care for these babies.	Thank you for your comment.
The Royal College of Midwives (RCM)	Short	General		The stratification of risk according to gestation will be very useful to health professionals providing the information.	Thank you for your comment.
The Royal College of Midwives (RCM)	Short	8		The priority given to good information giving to parents and carers is particularly welcome as we know there are serious short comings in this context. This area will have significant good impact but will need appropriate resourcing to ensure the relevant health professionals are able keep up to date with current evidence	Thanks for your comment. We agree that the appropriate provision of information to parents and carers is an important issue.
The Royal College of Midwives (RCM)	Short	9		*Information and support leading up to and on discharge* • *Before discharging a preterm baby : agree a discharge plan* We consider that this area will have significant impact but possibly challenging to implement in busy wards.	Thank you for your comment. We believe that all preterm babies should already have a discharge plan developed and so this should not be a significant impact.
The Royal College of Ophthalmologists	Short/Full	7 &11	General	In the absence of any simple validated (to NICE standards) assessment or test that paediatricians could use themselves (otherwise they would have to refer all these children to the hospital eye service) to pick up specific visual processing problems, it seemed sensible to suggest that they ensure that they check these children have the routine 4-5year vision screen as per the National Screening Committee recommendation. https://legacyscreening.phe.org.uk/vision-child	Thank you for your comment. The recommendations for the 4 year assessment include 'ensuring that the child has been offered orthoptic vision screening as recommended by the National Screening Committee' so is in line with your comment and the expert advice we received.

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*