Name	Comments	Response
Individual	**General comments** Overall good document, reads well, clear language, provides guidance. My concern, as with most things at present, is in relation to cost/finance and getting these services set up and running. **Specific comments** When considering infants who should be assessed, FASD is mentioned yet NAS is not? Many of these infants are placed into foster care and are at high risk of negative long term outcomes. Appendix 1 - may be helpful to include a column indicating which professional group could complete the assessment? This may be more helpful to areas that have no/limited AHP input. Although not a standardised assessment, should the Canadian Occupational Performance Measure (COPM) be included? This is often used to highlight specific areas of concern and guide parental goals and.	Thank you. We have added mention of neonatal abstinence syndrome, particularly in the context of needing pharmacological treatment, to the list of additional risk factors in Box 2. Appendix 1 already includes mention of the training requirements for each assessment, including if the developer recommends a specific professional. In all cases, these tools can be used by any professional with appropriate training and experience, so we do not want to limit implementation by listing those who can. The Canadian Occupational Performance Measure is recommended for children over 8 years, as it includes a self-assessment section (https://www.thecopm.ca). We also feel that the domains it covers are already incorporated in the existing assessments.
Individual	**General Comments** I like the document but am concerned that the example given has a nurse as part of the clinic in the 4 year developmental follow up. This role is best placed by a therapist who very clearly in their training has a better understanding of assessment of motor skills/ regulation etc. I would suggest that the model used is perhaps the Harrogate one where a therapist and psychologist lead the clinic showing much more holistic working and the importance of AHPPs. Another example in a national document of a senior nurse in clearly what is more suited to a therapy role is not helpful. **Specific comments** Appendix 2 example of a four year clinic set up.... comments as above	Thank you. Through this open consultation, we have now been able to find additional existing clinics willing to share their examples, including from Harrogate District Hospital. These are not provided as “gold standard” examples, more as examples of the various ways this clinic can be run.

Individual	**General Comments** Overall a very useful and comprehensive document. Feel it is really useful to have such strong recommendations for four year follow up. Particulary like the infographic for the pathway. Well done to all involved!	Thank you. We intentionally did not include the word “risk”, but have changed to “rate”. The NICE guideline does not actually mention a weight cut off, only being small for gestational age as a risk factor, which is included in Box 2.
	Specific comments Page 2, paragraph 2: Preterm infants have increased chances of developmental challenges. Wonder if risk or rates would be more appropriate than chances? Page 9 paragraph 2: include <1500g in NICE minimum guidance for two year follow up	
Individual	**Specific comments** - NAS babies not included in document - Feels like SALT could have had more of a voice; specifically around appropriate assessments and resources - The example of good practice - do we not have any services that have integrated AHPs to draw from?? Feels like a missed opportunity to showcase what a full MDT would/could look like.	Thank you. We have added mention of neonatal abstinence syndrome, particularly in the context of needing pharmacological treatment, to the list of additional risk factors in Box 2. There was a speech and language therapist within the initial working group throughout development, although for personal reasons they left prior to finalisation of the document and opted not to be included as an author. Other AHPPPs contributed to the working group at various times, and we sought extensive additional feedback from AHPPPs throughout the development. Through this open consultation, we have now been able to find additional existing clinics willing to share their examples. These are not provided as “gold standard” examples, more as examples of the various ways this clinic can be run.

Individual	**General Comments** From page 21: I think this is a very good draft. However, I think here at Harrogate District Hospital we have a better example than the Leeds Community. We have been following-up 4 year olds since 2022, and we have a full flow chart of how this is done, along with proformas for the report. We have a psychologist who uses the WPSSI, and analyses the 2 questionnaires we send - as recommended (Strength&diff, and Ages&Stages), then PT&OT carry out the SOGS, we then write a combined report and then decide who is feeding back to parents f2f. We then feedback and finalise the report, then send this to parents and to the paediatrician. The paediatrician then has this full report before seeing the pt for the 4year final appt. From the report, we do make referrals without waiting for the Paediatrcian. From experience this tends to be for autism assessment or/and speech and language therapy. I think this is a better example, as fully MDT, as we did not have extra funding as about 6 a year, as small DGH, therefore agreed would fit into PT/OT clinic and psychologist agreed to fit it in. We all (except Paediatrician) work on systemone, therefore have a task system and a designated admin clerk to send out the consent and explanation letter for all those meet criteria, then can all work on the same report and get appts booked in a timely manner and flow chart we can follow. I am happy to be contacted to add a lot more detail, if you want to use this as an example. **Specific comments** Please see above.	Thank you. Through this open consultation, we have now been able to find additional existing clinics willing to share their examples, including Harrogate District Hospital. These are not provided as “gold standard” examples, more as examples of the various ways this clinic can be run.
Individual	**General Comments** I think this is a very good document with helpful background, links and examples.	Thank you.

	Specific comments For those of us that do not normally see 4y olds, it is important that we receive training/support in assessing medical and behavioural issues that crop up at this age - how to assess, what advice to give and whom to refer onto locally. Eg screening for ASD is not something I would so myself as a neonatologist but recognise there is a risk of this in our ex prems and would want to make sure I was managing the 4y old patient properly.	We agree that training is likely to be required if this is a new role for the professional, and this will include standardised training for specific assessments as required. We have added more detail to this effect.

Individual	**General Comments** "I am delighted to see the progress with this document. However, it is entirely unacceptable that only 1 of the 15 working group members is an AHP and there are no Speech and Language Therapists (SLTs) on the working group for this important guidance document to inform the care of highly vulnerable children at significant risk of SLCN and health inequalities (Moser et al., 2008; Strand and Lindsay, 2012; Wren et al 2016; ONS, 2022). Communication is a fundamental human right (United Nations, 1948) and as such appropriate, specialist assessment at age 4 years must be included as a minimum requirement in this important national guidance document. To meet BANNFU's stated vision of facilitating 'appropriate intervention', the document must recommend the involvement of SLTs in the 4yo NDFU appointment. Currently, speech and language assessments are recommended to be carried out by non-specialist clinicians, which places high-risk children with specific speech and language needs at risk of being missed. Age 4 years is a critically important age for communication development and for addressing and supporting SLCN prior to school-entry. There is strong and compelling evidence of the importance of early specialist assessment for children at high risk of speech, language and communication needs (SLCN) and this document does not currently reflect this. The impact of SLCN is far reaching if it continues beyond early childhood (i.e., before age 4 years), leading to poor outcomes in education, employment and mental health (Felsenfeld et al., 1994; McCormack et al., 2009; Anthony et al., 2011; Wren et al., 2016). Annually, around 1.9 million children in the UK are at risk of SLCN (Speech and Language UK, 2023) and the vast majority of children eligible for 4yo NDFU are included in this number. The current level of SLCN in the UK is so great that it meets criteria to be considered a public health crisis (Law et al., 2017). This document must recognise this and make recommendations for appropriate specialist SLT assessment at this critical age. Within the current draft, the only mentions of 'speech and language' are with regard to a) pre-appointment information to inform 4yo NDFU and b) onward referral from the 4yo NDFU appointment. Pre-appointment information on SLCN is highly unlikely to be available for the majority of these children as SLTs are not routinely involved in prior 2yo NDFU and	Thank you. We acknowledge the importance of speech, language, and communication needs in this group of children. We have now been more explicit in including this wording throughout the document. There was a speech and language therapist within the initial working group throughout development, although for personal reasons they left prior to finalisation of the document and opted not to be included as an author. Other AHPPPs contributed to the working group at various times, and we sought extensive additional feedback from AHPPPs throughout the development. We agree that speech and language therapists will be valuable in the multidisciplinary team providing the four-year follow-up service. We already specify that involvement of allied health professionals is critical for a comprehensive developmental follow-up service. We cannot mandate involvement of speech and language therapists in the four-year follow-up appointments, as this will not be feasible for all services so may prevent any service being provided. Onward referrals may be required. We understand the challenges of speech, language, and communication assessment during existing follow-up prior to the four-year appointment. BANNFU hopes to develop an up-to-date best practice guide for two-year follow-up soon.

	community SLT services rarely pick up children before the age of 4-5 years (RCSLT). Further mentions of speech within this document are with regard to onward referral following the 4y NDFU appointment, by which time children can wait up to a year to receive intervention. The delay in referral and intervention leads to protracted periods of care which is burdensome on families and expensive for the NHS and society. It is therefore critical that SLTs are involved in NDFU. While the document rightly acknowledges constraints on NHS resources which may currently limit SLT involvement in any NDFU, it fails to make the case that SLT input is nevertheless critical to appropriate and timely identification of children at highest risk and with evident needs. Parents tell us they want SLTs to be involved in NDFU assessment and care. Parents are leaving work and using their life savings in order to fund private SLT for their VP-born children because timely NHS SLT support is not available through current NDFU care. BANNFU must lead the way in championing the need for SLT involvement in NDFU care so that we can build the evidence-based case for the inclusion of SLTs in the NDFU MDT and the development of subsequent support pathways. "	
	Specific comments Page 7 - Summary Recommendations must specify speech, language and communication as a domain requiring assessment at age 4 years. This is fundamental information for school start and for appropriate onward referral. It is not covered by cognition.	
Individual	**General Comments** Occupational therapists have the ideal skill set to assess a child's pre-school developmental abilities and I feel it would be more cost effective to have OT led clinics rather than medical led clinics. I also felt that some of the assessments in the index were a little outdated e.g. Bruininks-Oteresky	Thank you. We agree that occupational therapists will be valuable in the multidisciplinary team providing the four-year follow-up service. We do not specify these should be medical-led services, and advise that the team staffing these appointments will vary depending on existing structures. The assessments included were recommended by the AHPPPs within the working group and involved in additional feedback.

Individual	**General Comments** Fantastic document and really clear, thoughtful guide to 4 year follow up. I wonder if there is scope to offer a different approach to follow up with access to AHPs/Therapies to support and advice families during the appointments with specific interventions modelled/taught to parents so that they can activate and use these at home alongside referral onto community therapy services. We find that particularly for speech therapy, many services won't accept referral until 2,6-3years and then there is a long waiting list for initial assessments. By having a speech therapist present at 2yr and 4yr follow ups - specific activities/targets could be advised and modelled to families for them to work on while they wait for local assessment. We've also had one LNU within our region offer parent workshops around feeding between 5-6 mths for all babies born under 34weeks to support with weaning and more general advice. I wonder whether we need to think more broadly into parent/family groups, education resources and early intervention alongside the medical model of assessment/surveillance?	Thank you. We agree, and we specify that involvement of allied health professionals is critical for a comprehensive developmental follow-up service. We give examples of resources that may be appropriate to signpost to families, and these should be supplemented with local resources. We agree that interventions for this group that continue beyond the two- and four-year assessment would be valuable, but are outside of the scope of this best practice guidance. We acknowledge the importance of speech, language, and communication needs in this group of children. We have now been more

	Specific comments p6 para 2: Impact of prematurity on Speech, Language and Communication needs (SLCN) - could a sentence around this be added? P7. point 2. - Why has SLCN not been included as core domain? There is evidence around impact of SLCN on literacy and school achievement for children and the need for early intervention. Children that have been born prematurely are at increased risk of SLCN. Girls with SLCN and/or ASD can also sometimes mask their difficulties - particularly at 2 years - so there is need to look into these areas in more detail at 4 years using specific speech, language and communication assessments with an experienced SLT. P11 - Appointment - Excellent that it's clearly stated to be face2face - sometimes parents can unknowingly under-narrate the child's difficulties or the impact of these so it's really important to see the child. - Why has SLCN not been included as key area for assessment? I would argue that 'speech, language and communication' is a key area to assess - particularly with the impact these difficulties have in accessing the early year curriculum and school readiness. P12 - Excellent to include feeding problems - would it be useful to rephase to Eating and Drinking difficulties as talking about 4 year olds? Could you add in 'Sensory feeding difficulties and aversions'? and expand restricted diets to 'Allergies and/or restricted diets'? p18 - PLS-5 - recommended to be completed by a SLT - similarly to some of the psychological/cognitive assessments I think the PLS-5 should be idelly completed by a SLT who has the depth of knowledge and experience in speech and language difficulties and unpicking what the results show. Extra reference: systematic review. Rebecca Murphy is currently an SLT at Kings Hospital, London - she might have a more recent update on this publication. Harding, C., Levin, A., Crossley, S. L., Murphy, R., Van den Engel-Hoek, L. Effects of early communication intervention on speech and	explicit in including this wording throughout the document. We have amended wording to “eating and drinking difficulties”, and added in “sensory feeding difficulties and aversions, allergies and restricted diets”. For PLS-5, we have added “Recommended to be done by a speech and language therapist, educational/clinical psychologist and/or professional with appropriate training.” This reference describes valuable work, but outside of the scope of this best practice guidance.

	communication skills of preterm infants in the neonatal intensive care unit (NICU): a systematic review. J Neonatal Nurs 2019;25:177-88.	
Individual	**General Comments** The document does cover the fundamentals of how developmental follow-up might look for aged 4. The egs do not necessarily support the recommendations of the MDT working that is essential however.	Thank you. Through this open consultation, we have now been able to find additional existing clinics

	Specific Comments pg 11 - Appointment - needs to include sensory development and speech and language. pg 13 - Post appt - a good number of children seen are likely to be in school already - concerned that conversation re delaying entry into school needs to happen a while before their 4th birthday. pg 14 - implementing (admin support) - how do we keep track of children moving in/out of area? Is there a central place that can notify when a child moves out and into a new area to know to include in the followup programme? Potentially these children can fall between the cracks. pg 14 - team members -and same comment on pg 18 re Griffiths - states recommendation is that psychologist need to do Griffiths-III - this is not the case; AHPs can also carry out this assessment (following training) and this assessment covers a broad range of the child's needs which are the areas of speciality of AHPs. Taken from the official website - Paediatricians, Paediatric trainees, and Psychologists Paediatricians, Paediatric trainees, and Psychologists may be trained in the use of the Griffiths III Scales and can enrol directly for the first part (eLearning course) of the Griffiths III training on the ARICD website, after securing a place on a Practical Course. Allied Health Professionals (AHPs) AHPs (e.g., Speech and Language Therapists, Occupational Therapists, Physiotherapists and Specialist Nurses) may also apply if they are: Part of a Child Development Team, and Can be supervised by a Paediatrician or Psychologist experienced in the use of the Griffiths III Scales. Pg20 - resources and groups to signpost - There will probably be regional signposting that can also be given - e.g. in Cardiff and Vale we have a 'Keeping Me Well website that all therapies contribute to for parents, service users. https://keepingmewell.com/childrens-support-services/ Pg21 - appendix 3 - Just a comment - the document is showing a need for AHP input but this example does not show this	willing to share their examples. These are not provided as “gold standard” examples, more as examples of the various ways this clinic can be run. Although children may be in early years education at four years, we do not believe the majority will already be in school at this timepoint across the UK. We agree that the aim is to see these children prior to school entry, so planning timing with parental awareness of the need for assessment, and any other professionals involved with the child, will help identify the correct timing locally. We also hope that conversations around transition to school can begin at earlier follow-up appointments. BANNFU hopes to develop an up-to-date best practice guide for two-year follow-up soon. We agree it is important to identify children moving between areas. This will begin with early explanations to families about the importance of follow-up so they can advocate for their child and seek out assessment. GPs and health visitors are likely to be crucial to referring children in for appointments if they have moved to the area, so education to raise awareness for these groups is important. We have amended the wording regarding Griffiths training to make it more clear that any trained professional can complete this assessment. We have already mentioned identifying local resources alongside national resources to share with families. This looks like a useful local resource.

	pg 23 - appendix 4 - similar comment - A comment - this example does not include how AHPs need to be integrated into this model to ensure the assessment is carried out by appropriately skilled professionals for a comprehensive assessment of the child's needs.	
On behalf of Bliss	**General Comments** Bliss welcomes this comprehensive and well-evidenced draft guide, particularly considering the significant disparity between the proportion of neonatal units offering developmental follow-up at two years of age compared to those offering it at four years. The working group put significant thought into multidisciplinary collaboration and developmental outcomes for children that receive four-year follow-up. There are several areas in which the document could be strengthened, particularly around principles of family integrated care and inequalities. While the guide acknowledges the importance of caregiver input and consent, it could be more explicit to position carers as partners in care, not just informants or recipients. Bliss recommends co-produced care plans or shared decision-making models. It is welcome to see social deprivation listed as a risk factor and the recommendation of translation/interpretation services recommended. The guide could go further to recommend collecting and analysing ethnicity and socio-economic data in audits, as well as recommending use of culturally sensitive assessment tools and engagement strategies. Moreover, while acknowledging deprivation as a risk factor for adverse developmental outcomes is important, the guide does not explicitly address how deprivation affects access to follow-up services e.g. transport, childcare or digital exclusion, or what mitigations are needed.	Thank you. We have been more explicit that the summary report should include a care plan co-produced with caregivers. We have expanded our audit recommendations to include ethnicity and socioeconomic deprivation data to ensure equitable access. We have also added mention of the need for culturally sensitive engagement strategies, and the need to support engagement with and attendance at this appointment, mitigating challenges such as language, transport, and digital exclusion. We agree that using a national Index of Multiple Deprivation is not perfect for identifying those children vulnerable due to social deprivation. We give this as an example, and local teams may have a better system such as through screening questions or similar. Unfortunately, we know that other sociodemographic data is not as well

	Specific Comments Page 9, box 2, "Additional factors that increase risks of adverse long-term developmental outcomes" It is great to see the Committee recommend screening be offered to children with a least one additional risk factor in this box. We suggest including more guidance on how to determine the risk factor of social deprivation for individual children. Solely using the Index of Multiple Deprivation is likely to incorrectly flag children with this risk factor who aren't actually living with deprivation and conversely miss children who are in fact living in social deprivation. Page 11, paragraphs 2 and 6, "Pre-appointment" While the guide mentions paper and online formats, it doesn't explain why both are needed. Including digital exclusion as a rationale would acknowledge that some families may lack access to devices, internet, or digital literacy. Referring to the text which says "If children are not brought to the appointment, consider if this is a safeguarding concern", it would be valuable to include an action that needs to follow if this is felt to be the case. Page 11, paragraphs 7 and 8, "Appointment" It is welcome to see that this section recommends appointments are guided by any family concerns and questions and consider the psychological needs for the child or family. We suggest explicitly referencing the strains that navigating a complex care system can have on the sibling of a child born premature or sick, and the importance of signposting them to relevant services. Page 12, box 3, "The summary report after the appointment" As the summary report is one document which has multiple purposes to fulfil, using terminology suitable for an education provider's benefit may impact understandability for families. Additionally, if parents want further support or have concerns arising from the summary report, what is the next step for them? Are there provisions for the summary report to be	recorded as postcode, so give this as an easily implementable example. We hope this changes in the future. We have added the reasoning for different formats. We have added mention of using local "was not brought" policies to escalate as required. We have expanded mention of psychological needs to caregivers, siblings, and wider family members. We have added "this report may need to be adapted into a more accessible format for families". We have made it clearer this is "clinical teams", those delivering the service.

	made available in different formats where there might be language or communication challenges? Page 14, paragraph 3, "Implementation and training" Where the text says "Teams should look to develop links with education services locally...", it is not clear which teams are being referred to here.	
Individual	**General Comments** Overall a good document which highlights the gaps. Query if another summary recommendation should be to investigate where the funding for follow up is provided from , how it is distributed and investigations into how to provide a best practice MDT model throughout the country.	Thank you. We have expanded our audit recommendation to include the service provision as well as uptake and outcome. There was a speech and language therapist within the initial working group throughout development, although for personal reasons they left prior to finalisation of the document and opted not to be included as an author. Other AHPPPs contributed to the working group at various times, and we sought extensive additional feedback from AHPPPs throughout the development. We acknowledge the importance of speech, language, and communication needs in this group of children. We have now been more explicit in including this wording throughout the document.
	Specific Comments P3 Working Group Members - There is no representation from Speech and Language Therapy which is quite shocking considering the speech , language and communication needs of this population. Very disappointing. P6 Paragraph 2- 'Preterm infants have increased chances of developmental challenges, including cerebral palsy, cognitive impairment, visual/hearing impairment, attention deficit/hyperactivity disorder, autism, and poor educational attainment' - should include the increased risk of speech, language and communication (SLCN) which would cover receptive/ expressive language and social communication. P7 Point 2 - should include assessment of receptive and expressive language skills	

Individual	**General Comments** Absolutely love this-Such a valuable piece of work! My personal view would be that the minimum requirement should cover babies up to 34 weeks (Not just 28). From my work with various families, dults who were born pre-term and a qualitative study I conducted with Sarra Hoy, we constantly hear that the 'feed and grow' babies tend to have regulation and attention difficulties in later life that do not meet thresholds but do place a massive stress onto families. It would be great if this work could capture that gap as well. It would be good to have some more explicit consideration of how educational and clinical psychologists could be involved in the teams supporting children as they progress into school. Might there be a training need for those groups, for example? And should a CP and EP always be part of the support team? **Specific Comments** Page 6, line 1-Could add in 'and potential to thrive' in the first sentence, as this is what we would strive for by supporting developmental outcomes and that links in with the first 1001 days. Page 6, final paragraph-Worth adding in the cost of mental health services for parents as we know that MH can be negatively impacted by struggling to get the right support for children, or having to manage challenging behaviours that can arise because of dysregulation. (https://www.sciencedirect.com/science/article/pii/S0022347613013875; https://www.mdpi.com/2227-9067/10/9/1565)	Thank you. We agree that late preterm babies are also vulnerable. If local services currently include these infants within their follow-up criteria, they would be included in the “strongly considered” group in this guideline. We agree that psychologists will be valuable in the multidisciplinary team providing the four-year follow-up service. We already specify that involvement of allied health professionals is critical for a comprehensive developmental follow-up service. We cannot mandate involvement of psychologists in the four-year follow-up appointments, as this will not be feasible for all services so may prevent any service being provided. Onward referrals may be required. Training needs for all professionals involved in follow-up should be identified. We have made this more explicit. We have added “to give them the potential to thrive”. We have added a reference to support the need for supporting family members with their mental health.
On behalf of St. Mary's Hospital Newborn Services	**General Comments** In preparing a response we have discussed the proposed guideline as a consultant group and have liaised with the lead for Community Paediatrics in Manchester. Whilst nobody disagrees that following up extreme prems to four years old as a minimum may be a good idea which enhances opportunities to pick up evolving issues, there are significant concerns about the resources required for this, both in neonatal/paediatric settings and in community.	Thank you. We agree that additional funding and resources may be required, and we understand the challenges in this. We have provided an example of a successful business case to try and support local teams with this. We wish you luck in establishing this service in the future.

	Specific Comments With already significant shortages in AHP cover (and clinic availability in some hospitals) within neonatal services it is not deemed feasible to extend the neonatal follow-up period to four years, so the increased follow-up requirements would no doubt fall to community paediatrics. Community paeds in this area offer enhanced follow up in a bespoke way, for those that are identified as in need. For example, they link in with educational psychology early as needed via section 23 notification. Manchester community paediatrics do not have any psychology support available at all in their service currently, and are not offering Griffiths or WPPSI currently due to training implications and time requirements. As described on page 14 of the document, there are significant funding gaps in follow-up resources, ranging from admin support to consultant and AHP availability. It is described that appointments should be allowed 60-90 minutes, which would certainly be needed for thorough assessment but which would be need to be adequately timetabled which all the personnel required. In summary, it is not felt that routine follow up of all extreme prems is currently feasible in the Manchester area, however with adequate investment into required resources it is felt that this service would benefit ex-NICU babies and their families.	
Individual	**General Comments** The document is generally comprehensive, well laid out and useful. The business case proforma is helpful.	Thank you.

	Specific Comments Box 2 on p.9 lists the additional factors increasing risks for our ex-neonatal population. Although social deprivation is listed as an additional factor, children under the care of social services (either as CiN, CPP or looked after) are not listed. These children may not fall under the category of social deprivation, especially if they're looked after. It's known that, ""The percentage of pupils in the key social care groups that have a special educational need (SEN) is over twice that for the overall pupil population."" (https://explore-education-statistics.service.gov.uk/find-statistics/outcomes-for-children-in-need-including-children-looked-after-by-local-authorities-in-england/2024) In the same box, too, there is no mention of the effects of needing long-term ventilation. Again, it's known that long-term ventilation has a higher risk of neurodevelopmental difficulties in childhood (https://pmc.ncbi.nlm.nih.gov/articles/PMC8313736/pdf/fped-09-689190.pdf) I wonder if you would consider including these two as additional factors?	We have added children under the care of social services to the Box 2. We believe that those requiring long-term ventilation are included in “bronchopulmonary dysplasia”.
[redacted]	[redacted]	[redacted]

On behalf of Thames Valley And Wessex Neonatal ODN AHP	**General Comments** 1. Limited Added Value a. The document does not provide significant updates or improvements to existing processes for 2-year assessments. b. It also does not adequately address why 4-year assessments are currently not happening or how these barriers could be resolved. 2. AHP Representation a. The vision states that it was developed by a multi-disciplinary team, but there is under-representation of Allied Health Professional (AHP) input. b. Greater AHP involvement in drafting and reviewing the document would have strengthened its relevance and applicability. 3. Lack of Specificity a. The guidance is too high-level and non-specific, limiting its usefulness for implementation. b. A clearer definition of what a “Gold Standard” assessment process should look like would help inform business cases, service planning, and resource allocation. 4. Clarity on Roles and Costs a. It would be helpful to specify who should carry out 4-year assessments. b. Evidence suggests that AHP-led clinics could significantly reduce costs while maintaining high-quality care. 5. Assessment Tools and Consistency a. The large number of potential assessments listed (some outdated) makes it difficult to achieve cross-organisational consistency. b. This variability impacts: i. Data comparability ii. Identifying areas of need iii. Producing cohesive, standardised report templates that are helpful for families and professionals. 6. Alignment with NHS Strategy	Thank you. Two-year follow-up is out of the scope of this four-year follow-up best practice guide. BANNFU hopes to develop an up-to-date best practice guide for two-year follow-up soon. We have aimed to address the known barriers as to why four-year follow-up is not currently universal. This includes widening the assessments that can be considered to provide staffing options, clear numbers of who should be included, and support for funding, through providing a successful business case. Various AHPPPs contributed to the working group throughout, and we sought extensive additional feedback from AHPPPs throughout the development. Best practice guidance is intended to be high level, to allow a degree of local variation in implementation, aiming to address the barriers previously mentioned. We describe the minimum required, both in terms of those to be assessed, and assessments needed, but also expand on those we would recommend including as best practice. We have provided a list of the domains that require assessment, and provide a range of potential assessments to allow local services to utilise current professionals and current skill sets. The assessments included were recommended by the AHPPPs within the working group and involved in additional feedback.

	a. The document should explicitly align with the NHS 10-Year Plan, particularly the goal to eliminate routine outpatient appointments at hospitals by 2035. b. Service design recommendations should reflect this strategic shift. 7. Presentation a. The document is well-structured and concise, which is positive. However, its content lacks clarity and practical guidance. 8. Co-ordination of the Service The document states that this role should be provided by the Neonatal Networks to oversee, co-ordinate and monitor data collection. There is currently no specific role and no funding to support this and therefore this will not be possible in the current climate. If a role was created to supported this, it should be considered for an AHP – these roles are often targeted at nurses who are not involved in the follow up process. It should also be backed with protected admin support in all involved provider units.	In terms of data comparability, a four-year form for data collection will be developed. A similar challenge, in terms of varying assessments performed, already exists at two-year follow-up. The report focus should be centred around the needs of the child and family. It would be valuable for local teams to develop standardised report templates for local services, describing the assessments used locally. The NHS 10-year plan applies only to England, and this recommends adapting how outpatient appointments are organised. Local teams should give consideration to the longevity of the service at implementation.

	Specific Comments Diagram – Page 8: Ecosystem of Developmental Follow-Up • Move the explanatory text before the diagram to make it clearer. • The diagram is visually busy and difficult to interpret: o Delete the three bullet points within the image and emphasise SPA instead. o Clarify the meaning of “pathways into service”—does this refer to the 4-year assessment clinic? • The explanatory text on page 10 is better and sufficient—consider simplifying the diagram accordingly. Consent and Service Descriptions • Add other healthcare professionals/services to the consent bullet points. • Clarify the meaning of “Child Community Health Centre”: o Is this a GP practice, neighbourhood clinic (aligned with the 10-year plan), or something else? Face-to-Face Appointments • Specify who conducts these and where they occur: o Neonatal teams? o Community services? o MDT clinics? Children Qualifying for Assessments • The section appears contradictory: o Is eligibility based on Box 1 or all children qualifying for the 2-year assessment? • Best practice guidance should commit to a clear and consistent standard. Identifying Children – Page 10 • The process is overly complex and non-specific. • A simplified flowchart would be far more effective for decision-making. Appointments – Page 11 • Clarify where best-practice assessments should occur and by whom:	Operational Delivery Network feedback was sought prior to open consultation. We are advising Network overview, not direct delivery. We agree that additional funding may be valuable. We have already highlighted the need for local administrative support. We have advised moving the figure to later in the document. This figure is a summary of the entire developmental assessment process described within the best practice guide. Within the figure, we have added “other healthcare professionals” to the consent bullet point. We have reworded to “community paediatrics”. We have specified within the best practice guidance that the location and teams providing this service will vary depending on existing structures, but involvement of allied health professionals is critical for a comprehensive developmental follow-up service. This may include neonatal and/or community teams, as shown by existing services. This best practice guidance gives a minimum of Box 1, strongly advising including all children qualifying for two-year follow-up locally, and considering those with additional risk factors included in Box 2. We do not believe this is contradictory. Unfortunately identifying children is a complex process, because although the majority will be identified from two-year follow-up, others will move into the area. This process is summarised within Figure 1.

	o Should they be in neonatal outreach teams, community clinics, or elsewhere? • Given the NHS 10-Year Plan goal of reducing hospital-based outpatient appointments, service planning must reflect this. • Consider adding decision-making prompts to guide local service discussions rather than leaving it at "as per local agreement." • Combine this section with "Team Members" (page 14) to improve flow and cohesion. Team Roles and Responsibilities – Page 14 • Define clear responsibilities for the 4-year assessor, including: o Initiating and coordinating EHCP processes. o Overseeing neonatal-to-community transitions. • Consider presenting this information as a role-and-responsibility matrix for clarity. • The developmental review section would be more usable as a printable checklist. Appendix 2 – Resources • The resources are heavily OT-focused and lack breadth. • Consider including: o Motor assessment tools o Autism resources o Language group materials o SENDIASS o HIE PEEPS and other relevant resources. • GMFM / MACS are mentioned in body of assessments but have been missed off Appendix list Key Recommendations 1. Define a "Gold Standard" for 4-year assessments to provide a benchmark. 2. Clarify roles, responsibilities, and locations for assessments, including AHP-led options. 3. Standardise assessment tools and reporting templates to enable cross-organisational comparisons. 4. Simplify decision-making using flowcharts and checklists where appropriate. 5. Align the document more explicitly with the NHS 10-Year Plan.	The location and teams providing this service will vary depending on existing structures, and may include neonatal and/or community teams. If applicable (i.e. based in England), local services should consider the NHS 10-year plan implementation during their local decisions around implementation. Unfortunately creating a decision-making prompt that would include all the local considerations relevant to developing these services is outside the scope of this best practice guidance. We have included a range of information important for local teams to consider, including assessments and staffing options, and costing. We believe that our description of location and team members are best placed in the section around implementation, as this is when these are determined. The responsibilities of the four-year assessor will vary depending on how this is arranged locally – for example the coordination of EHCP (in England) may not be best placed with this professional. This process may also change in the near future with government policies. A role-and-responsibility matrix, and a developmental review checklist, may be valuable to be developed locally. Regarding resources, we have already highlighted that teams should identify additional local resources and services to signpost. We have already included motor assessment tools and resources for neurodiverse children. We have added PEEPS.

	6. Increase AHP representation in future revisions to strengthen practical relevance. 7. Streamline diagrams and improve visual clarity for better usability.	We aimed to include resources that are accessible across the UK. Although SENDIASS is only for those in England, we have now added this. GMFCS and MACS are scores for those with cerebral palsy, not assessments, so were intentionally not included in Appendix 2.
On behalf of National Neonatal Network Lead Physiotherapists	**General Comments** We really value this document and appreciate the amount of work it has taken to get to this point. With some further refining it will be a really valuable tool to help local areas to set up standardised 4 year follow up services. We do however feel that as with everything, appropriate funding for services is going to be a real struggle.	Thank you. There was a speech and language therapist within the initial working group throughout development, although for personal reasons they left prior to finalisation of the document and

	Specific Comments • There was only an OT on working party for this guideline – disappointing not to see SLT as well considering the social communication difficulties so many of the high risk infants have. • Whilst we understand this is a four year follow up guidance document, it doesn't mention any previous follow up at all - would it be useful to refer to a follow up pathway in the vision section? We are assuming this document will later be joined by something about 2 year follow up etc? Is there a timeframe for this? • Pg7 point 2 – communication/ social communication skills should be included in this list too • Recommendation 4 in the summary states ""Neonatal networks should oversee and promote coordination of follow up at four years of age, and collation of information for monitoring the service"". There is currently no specific role and no funding to support this and therefore this will not be possible in the current climate. If a role was created to supported this, it should be considered for an AHP – these roles are often targeted at nurses who are not involved in the follow up process at all. Recommendations for a follow up coordinator have been identified in the briefing paper from London. Funding needs to be considered. • Whilst we do not feel physiotherapy has a huge role in the 4 year assessments, currently it is often the physios who are involved in the 2 year follow up so they may be a really useful link to help to set up/coordinate the 4 year follow up services. • Pg8 – blue box at bottom – is a physio really needed for the assessment? It has been tried it some areas and it didn't add any value. • Pg9 – there should be something here about a staged approach e.g. starting with key infants < 28 weeks and HIE cooled and build as the clinic develops. The risk is teams saying they can't do follow up at 4 due to high numbers of children needing to be seen/costs so no one gets seen. There should be further information around bare minimum vs gold standard, otherwise everyone will just aim for the minimum which falls short of what our patients need.	opted not to be included as an author. Other AHPPPs contributed to the working group at various times, and we sought extensive additional feedback from AHPPPs throughout the development. Earlier follow-up is out of the scope of this four-year follow-up best practice guide. BANNFU hopes to develop an up-to-date best practice guide for two-year follow-up soon. We acknowledge the importance of speech, language, and communication needs in this group of children. We have now been more explicit in including this wording throughout the document. Operational Delivery Network feedback was sought prior to open consultation. We are advising Network overview, not direct delivery. We agree that additional funding may be valuable. We agree that a follow-up coordinator for each network would be valuable, but this is not a role we have suggested within this document. We agree that involvement of allied health professionals is critical for a comprehensive developmental follow-up service. We are advising that the team providing the four-year follow up service will vary depending on existing structures, and this may include physiotherapists. This best practice guidance gives a minimum of Box 1 (<28 weeks and neonatal encephalopathy), strongly advising including all children qualifying for two-year follow-up locally, and considering those with additional risk factors

	• Pg11 Appointment – first paragraph - says should be face to face but this can be challenging in rural areas / or with children with additional needs so there needs to be another option of what a virtual clinic appt could look like (although F2F would be optimal, it is better to have a virtual appt than none at all if parents can't attend) • Pg14 – implementation and training, first paragraph – not enough hours to oversee this in the network – will need additional network funding and this should be written in to the document – e.g. a follow up coordinator for each network, with a funding stream identified. • Pg14 – grammar - A four-year developmental follow-up page is under development for within Badgernet, - re word an omit 'for' • Appendix 1 – GMFM has been mentioned earlier in the document but don't have it in the appendix. Should this be added? • There are other assessments out there e.g PDMS, DAYC, Sensory Profile, Sensory processing measure and other fine motor/pre-writing skill assessment. Not sure if there needs to be a more comprehensive list or equally it needs to be reduced to advise 2-3 recommended assessments to ensure standardisation for info gathering? With so many assessment choices how do people choose which is best for their service, especially as almost all services will be starting from scratch, and how can we collate any national datasets if there is so much variety. If there was better AHP & psychology collaboration for this document there could be a consensus of the optimal ones to use. The assessment provided should meet the needs of the child e.g. if communication is very delayed should focus on that area. As an example , if they send out the SDQ to parent and early years providers before, they can review and see where they need to focus their assessment.	included in Box 2. We agree that both no service and minimum service are not gold standard, and have tried to describe this balance to the best of our ability. We feel that face-to-face is optimal, and that virtual would not provide an adequate assessment. We fear that providing a virtual option in this document would mean that this may be all that is provided. We have deleted "for". GMFCS and MACS are scores for those with cerebral palsy, not assessments, so were intentionally not included in Appendix 2. We have provided a list of the domains that require assessment, and provide a range of potential assessments to allow local services to utilise current professionals and current skill sets, or identifying specific training requirements. We agree that there are other possible assessments that could be included – we have now included your suggestions after further discussion. The assessments included were recommended by the AHPPPs within the working group and involved in additional feedback. This list is the result of a balance between narrowing down and excluding some that duplicated those included, and still covering the required domains regardless of the staff available for the appointments (i.e. not limiting to those that need a specific professional).
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On behalf of Ashford and St Peter's Hospitals	**General Comments** Many thanks for the fantastic work of creating this comprehensive draft. It is no doubt that the 4 year follow up in a holistic way involving all AHP team is paramount for all high-risk infants, especially with increasing proportion of extreme preterm babies being offered active management and intensive care compared to few years ago. The points we wanted to raise are below: • The draft guideline has kept the recommendation general with regards to who is responsible to do the follow up as below: 'Four-year developmental follow-up may be embedded within neonatal services, within general paediatrics if there are staff members with a developmental interest, or within community paediatric services' The details of the follow up requested will be beyond the scope of a Neonatologist, even with additional training. It would be very challenging for Neonatologists to be doing this, and we feel that Community Paediatricians would be best placed for it. The example provided in Appendix for a successful business case from the Leeds community services seems to prove this. We think, it's best to recommend that the 4 year follow up be conducted by Paediatrician with developmental interest or much better Community Developmental Paediatrician. • The responsibility to oversee the implementation, co-ordination and monitoring has been given to Neonatal networks. We are not sure how this is feasible if community Paediatrics would be the best team to deliver this service. • The recommendation of reporting through Badgernet tool which would not be easy to do if other teams (Paediatrician / Community team) would be the most common choice for carrying out the assessment. From experience we know that it is so difficult to get data from other teams to input into Badger. It could lead to excessive admin time for the Neonatologist to chase and collect data and there could be risk of data loss. It's best that another portal is created that is accessible by all professionals.	Thank you. Four-year developmental follow-up may be embedded within neonatal services, within general paediatrics if there are staff members with a developmental interest, or within community paediatric services. These variations all currently exist across the UK. We recommend that local services decide where this follow-up is best placed for them. Regardless of where follow-up takes place, we believe that neonatal networks should maintain oversight to ensure that follow-up services exist. Operational Delivery Network feedback was sought prior to open consultation. This data is important to neonatal teams for local services and benchmarking. How outcome data is identified effectively will need to be considered depending on local arrangements. We are beginning development of a four-year developmental follow-up page. Badgernet remains the key system for neonatal network data. We believe that four-year follow-up data is crucial for the National Neonatal Audit Program to effectively conduct national surveillance, benchmarking, and service provision planning, as well as research. We agree that creation of a portal for local professionals of different specialities to share information would be valuable but is outside the scope of this best practice guideline. We have changed "health" to "healthy", and "Brazilian" to "Brazilian Portuguese".

	Additionally, we think that the suggestion of this being adapted by NNAP as one of its measures is also not appropriate, as Neonatal teams are not best placed to deliver this service.	
	Specific Comments There was also a small typo: Page 11 - “encouraging vitamin supplements alongside a health, balanced diet (vitamins A, C and D are recommended from six months to five years of age)"" It is written as health instead of healthy. Page 18 - the draft says Brazilian language in the table at Griffiths Scales of Child Development, 3rd Edition (Griffiths III) - Brazilian Portuguese might be a better choice.	