NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Developmental follow-up of children and young people born preterm

Date of quality standards advisory committee post-consultation meeting:
13 February 2018

2 Introduction

The draft quality standard for developmental follow-up of children and young people born preterm was made available on the NICE website for a 5-week public consultation period between 15 December 2017 and 19 January 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 15 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Most stakeholders supported the quality standard and felt that it includes the key areas for quality improvement.
- Stakeholders felt that the statements promote multidisciplinary working, the role of allied health professionals in follow-up, continuity of care, and putting families at the centre of care.
- Support for the statements that include communicating with GPs about neonatal service involvement in the care of children and young people born preterm.

Consultation comments on data collection

- It should be straightforward to collect data for statements 1, 2 and 3.
- For statement 4, systems are not currently in place for community paediatricians to submit data on the review at 4 years.
- Staff training for clinicians and regular reviews of the data might be needed to ensure accurate and reliable data is captured.

Consultation comments on resource impact

- There is a shortage of dedicated neonatal physiotherapy posts: most have to combine neonatal follow-up with a caseload of all children in the community.
- There is the potential for cost savings from neonatal physiotherapists carrying out enhanced developmental surveillance independently, rather than with a consultant, and referring to other services if needed.
- The review at 4 years is additional activity and is not achievable without more investment.
- Concerns around the statements increasing the number of appointments and outreach provision, and whether the required resources are available.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Parents or carers of a preterm baby agree a discharge plan with maternity services.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- The discharge plan should be agreed with neonatal services instead of maternity services, or agreed with maternity and neonatal services.
- Rooming in with the infant to support the transition to home should be part of the discharge process.
- Include ‘signposting to local services’ in the rationale when referring to information for families.
- The structure measure could include evidence of neonatal units having occupational therapist representation on their multidisciplinary team to support discharge planning.
- Varying opinions on whether it is possible to measure the statement through Badgernet:
  - maternity services do not have a record system that links with Badgernet, so a national reporting system would be needed
  - documentation of discussing discharge with parents should be linked to the neonatal inpatient record (Badgernet) so compliance can be monitored
  - it is possible to measure the statement with Badgernet currently.
- Comments on the outcome measure:
  - a parental survey could be developed to measure this with minimal financial implications
  - this is not linked to discussing discharge planning with parents or carers
  - the neonatal survey in the data source would need to identify the gestational age at birth to reflect that the correct type of discharge planning was done.
- Include allied health professionals and neonatal outreach teams in the audience descriptor for healthcare professionals. Allied health professionals can inform

parents and carers of the role of therapy after discharge; occupational therapists promote parent confidence in caring for their baby, can assess the suitability of the home environment, and advise whether specialist equipment is needed for babies with complex needs.

- State in the audience descriptors that parents should receive a written copy of the discharge plan and emphasise that they are supported to proactively input into developing the plan.
- Comments on the definition of the discharge plan:
  - a frequently asked questions sheet could be provided at discharge
  - include neonatal outreach services
  - the NICE guideline on postnatal care up to 8 weeks after birth is referred to, but it does not say whether this is corrected age, or recommend what should be done if a baby is discharged after 8 weeks
  - add information on the following:
    - advice for GPs on key milestones to be aware of
    - referral to allied health professionals
    - multidisciplinary team plans
    - realistic expectations for complex families
    - that support is available from local or national services provided by statutory, voluntary/community or private sector bodies, such as Bliss, TAMBA, Scope and NCT.

5.2 Draft statement 2

Parents or carers of a preterm baby who is eligible for enhanced developmental support are provided with a single point of contact for outreach care within the neonatal service.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- The outreach team needs to be based locally, responsive, and does not need to be a neonatal outreach team. It could be other groups with similar expertise, such as community children’s nursing teams.
- Neonatal and/or paediatric consultants providing ongoing care should be involved in, or notified of, contacts with neonatal outreach.
- By the time of discharge, most babies are in the paediatric age bracket rather than neonates.
- It is not clear how long a baby should be under neonatal care. There should be a seamless transition to paediatric community care and a continued single point of contact for complex cases.
- Change ‘reassurance’ to ‘support’ in the rationale.
- The structure measure could include evidence of neonatal units having occupational therapist representation on the neonatal outreach team to staff the single point of contact.
- The process and outcome measures are possible to measure.
- The outcome measure is not linked to the process of having a single point of contact.
- Add text on the neonatal outreach service to the service provider and parent and carer audience descriptors.
- Comments on the definition of the single point of contact:
  - include face-to-face meetings or home visits
  - it is unclear what the support should be, the hours it should be available, an acceptable response time to emails or messages, and what a parent should do if they have a serious concern but the support is not immediate

- there should be a process to ensure that babies discharged from units outside their network can be followed up by neonatal outreach locally.

5.3 Draft statement 3

Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up visits in the first year and an assessment at 2 years that focus on development.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Implementing the statement will place an additional burden, including a financial burden, on health visitor provider organisations.
- Concern that specifying that there should be 2 follow-up visits in the first year will result in services that perform more visits than this reducing the quality of care they provide.
- The supporting sections are inconsistent on whether the allied health professional should be present at the visits, or available through referral.
- Measure the offer of follow-up visits, rather than receipt, as attendance is out of the clinicians' control.
- The process and outcome measures are possible to measure.
- The 'red book' is not a reliable data source, and Badgernet is the only assured source.
- Where 'specific tools' or 'standardised assessments' to detect developmental problems are referred to, these should be specified.
- State in the audience descriptor for healthcare professionals that occupational therapists should be part of the core multidisciplinary team.
- The patient audience descriptor should include signposting parents or carers to local or national organisations who can offer them practical or emotional support.
- The definition of enhanced developmental surveillance should include babies with severe hypoglycaemia.
- Comments on the definition of the follow-up visits and 2 year assessment:

  - concern that the PARCA-R is the only screening tool suggested and suitable alternatives are not specified, such as for people who are non-English speaking.
  - the Ages and Stages questionnaire-3 should be added as a suitable alternative if PARCA-R cannot be used
  - Bayley III is currently used at the 2 year assessment and staff training might be needed to change to PARCA-R
  - add discussing with parents or carers if they have any concerns about their child's feeding
  - clarify whether a Gross Motor Function Classification System (GMFCS) level or a Gross Motor Function Measure assessment score is required if cerebral palsy is identified at the 2 year assessment
  - the GMFCS extended and revised version should be used to measure motor function, as this covers the correct age range
  - include a tool to measure manual ability in those with a diagnosis of cerebral palsy
  - include collecting information on current medication, and acute or chronic illness.

5.4 Draft statement 4

Children born before 28^{+0} weeks' gestation have a developmental assessment at age 4 years.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- It will be difficult to keep track of and re-engage with children needing follow-up at 4 years, in particular if they have been discharged from neonatal follow-up.
- Community paediatricians do not have access to the data systems to find out which children need the assessment.
- This statement would be hard to achieve within current local structures as it requires funding, and an extension to staff capacity and clinic facilities of the

community paediatric multidisciplinary services, or it would need a new service to deliver it.

- The rationale should be clearer that not all developmental problems will have a diagnosis, as some children may have a ‘syndrome without a name’.
- Data collection systems to capture information on the 4 year check need to be standardised and accessible for audit.
- Comments on the audience descriptor for healthcare professionals:
  - include educational professionals and access to allied health professionals
  - most local authorities do not have enough educational or clinical psychologists and they need to be specifically commissioned.
- Comments on the definition of the developmental assessment:
  - it is not possible for healthcare professionals to ensure that orthoptic vision screening has been offered at this check, as it is offered between 4 and 5 years of age, and screening can take place at any point up to 5 years 10 months.
  - add discussing with parents or carers if they have any concerns about their child’s feeding
  - a standardised test should be used to assess speech, language and communication needs, such as the Preschool Language Scale-4 Screening Test.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	NHS England	General	The standards are all related to specialist neonatal services, rather than primary care, however, I am pleased to note that the standards recommended include dialogue with patients' general practitioners. We don't have any comment to offer from general practice point of view other than that we are pleased to note that standards include communication with primary care practitioners about involvement of neonatal service in providing care to children and young people born preterm.
2	Royal College of Paediatrics and Child Health	General	There seems to be an overall paucity of research on the value of the assessments described. Interestingly not much better than 30+ years ago.
3	Royal College of Paediatrics and Child Health	General	Nice should be as clear on what is NOT needed as what is if possible
4	Association of Paediatric Chartered Physiotherapists	Question 1	'Does this draft quality standard accurately reflect the key areas for quality improvement?' Overall the quality standards are good and will provide a way of monitoring the guidance. If followed they will provide families with more support and put families at the centre of care. It also promotes MDT working which is key to our role with this vulnerable population and supports the importance of the role of the AHP in being part of neonatal follow up services for high risk infants.
5	British Association of Perinatal Medicine (BAPM)	Question 1	1. Does this draft quality standard accurately reflect the key areas for quality improvement? Yes
6	Royal College of General Practitioners	Question 1	This quality standard accurately reflect the key areas for quality improvement. It is vital for parents to have continuity of care from both primary and secondary care
7	Association of Paediatric Chartered Physiotherapists	Question 2	'Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?' Statement 1 – data could be easily collected by the individuals involved in providing the service

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
			Statement 2 – data could be easily collected by the individuals involved with this service, and services are likely already collecting this information. Statement 3 – with most units using BadgerNet (in varying capacities) to enter information this should be quite straightforward to collect, as well as NNAP data. However this does rely on timely and accurate data inputting by clinicians so staff education will be important with regular reviews to ensure this information is being captured. Statement 4 – as above the use of BadgerNet to identify the appropriate patients will be important however there is a risk of a larger proportion of babies being lost to follow by 4 years, especially from large city centre hospitals that have transient local populations so tracking of these patients to 4 years may be challenging.
8	British Association of Perinatal Medicine (BAPM)	Question 2	2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures? No The key area where systems are currently not in place is for the review and reporting of outcomes at 4 years. BAPM is reasonably certain that these assessments will mostly be undertaken by Community/ Local Paediatricians rather than Neonatologists, and will require local structures to be developed to: a) Notify community practitioners of the cases following discharge from neonatal follow-up and b) Submit data regarding these reviews We believe the estimate of potential cost as stated on the NICE website is a gross understatement.
9	Royal College of General Practitioners	Question 2	It would be useful to include the SNOMED clinical terms for this standard so that NHS secondary care trusts can use a standard methods or coding the data to measure their performance to these standards and not to rely on paper based audit and quality improvement. SNOMED CT must be adopted by all GPs and in systems used by general practice service providers, before 1 April 2018 and by secondary care by 1 April 2020
10	Association of Paediatric Chartered Physiotherapists	Question 3	'Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.' 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.

ID	Stakeholder	Statement number	Comments[1]
			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 physiotherapist as part of the neonatal follow up MDT in a dedicated role. In terms of cost savings, the use of specialist neonatal physiotherapists to carry out the enhanced developmental surveillance as an independent practitioner, rather than all follow up appointments being led by a consultant and a therapist, would certainly help drive costs of follow up clinics down. Neonatal physiotherapists have the specialist skills needed to assess all aspects of development and can then make timely referrals to other services as required following assessment. The Edinburgh neonatal follow up service is run by a specialist neonatal physiotherapist, and they have a very low DNA rate and have 90% outcome data at 2 years (national average 54%). This could be used as an example of good practice when managers are looking at how the service can be costed and staffed. Great caution should also be taken when using these guidelines as evidence to support cutting back services that are currently offering more follow up appointments as part of their already established high risk follow up service. The guideline recommends just two follow up visits in the first year which we do not feel is sufficient (see comment 10 on statement 3) and certainly dictates a bare minimum, rather than a gold standard service. Further clarity needs to be made on this in the quality statements to ensure currently excellent services don’t face funding cuts with the quality of patient care being adversely affected. Redesigning clinics to reduce consultant cost in exchange for therapy time as previously mentioned would help make those savings without downgrading the quality of the service provided to the patients.
11	British Association of Perinatal Medicine (BAPM)	Question 3	3) Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment. Not achievable without considerably more investment than stated on the NICE website. I do not see that there is a potential for cost saving as undertaking a review at 4 years for all these babies is additional activity.
12	Royal College of Nursing	Question 3	We support this quality standard, however, do question the resource issue that would support effective implementation as the proposed statements will potentially increase the number of appointments and also could result in increase in outreach provision. We hope that this has been taken into account and resources are being provided.

ID	Stakeholder	Statement number	Comments[1]
13	Association of Paediatric Chartered Physiotherapists	Statement 1	‘Healthcare professionals (such as midwives, neonatal nurses and neonatologists)’ There is a clear and significant role for Physiotherapy/Occupational Therapy (a neurodevelopmental specialist) to be involved in the discharge planning process. Neurodevelopmental surveillance should begin on the neonatal unit. The standard specifically highlights "risk factors for developmental problems and disorders, support available and follow-up arrangements." This is a clear exclusion of AHP's with the skills required, and who are usually (and will be more in the future) involved in follow-up and on NICU.
14	Association of Paediatric Chartered Physiotherapists	Statement 1	‘Discharge Plan’ Physiotherapists/Occupational Therapists have a key role in imparting important developmental information to parents prior to discharge and informing them of the therapy role for their baby upon discharge
15	Bliss	Statement 1	Discharge planning should be agreed by parents and neonatal services. I’m assuming maternity has been stated here because of coordination by Local Maternity Systems, however this will be operationally delivered by the neonatal service.
16	Bliss	Statement 1	This should also include “signposting to local services” in the information provided for parents.
17	Bliss	Statement 1	Again this should be referenced as neonatal services rather than maternity.
18	Bliss	Statement 1	Again this should be referenced as neonatal services rather than maternity.
19	Bliss	Statement 1	This list should also include neonatal outreach teams, neonatal physios and therapists.
20	Bliss	Statement 1	‘They share the written discharge plan with parents or carers and with primary and secondary healthcare teams’ Would suggest amending to say something like ‘Discharge plans are developed with parents or carers, who receive a written copy of what they have agreed, and this can be shared with the secondary healthcare teams’. In its current format, it seems as if parents are not involved in the discharge planning process.
21	Bliss	Statement 1	Suggest final sentence is amended to say ‘They are supported to proactively input into and agree a written discharge plan….’ To again reinforce the importance of parental involvement.
22	Bliss	Statement 1	Neonatal outreach service (where available) to be included on this list
23	British Association of Perinatal Medicine (BAPM)	Statement 1	This appears to be all about discharge planning but the ‘Outcome' (parents who feel prepared for their baby’s discharge from maternity services) has absolutely nothing to do with the process listed above: in reality, many parents facing the prospect of taking a preterm baby home feel ‘unprepared’, but this is a subjective measure. We propose the development of nationally agreed written information for parents of preterm children to facilitate discussion and agreement around follow up, with documentation that this discussion has been undertaken.

ID	Stakeholder	Statement number	Comments[1]
			We recommend strongly that, as with documentation of follow up, documentation of such discussion is linked to the commonly used neonatal inpatient record (Badgernet), allowing individual units easily to monitor their own compliance
24	Department of Health and Social Care	Statement 1	Nil return from DHSC Maternity team
25	NCT	Statement 1	It is suggested that parents/carers agree a 'written discharge plan that includes tailored information on risk factors for developmental problems and disorders, support available and follow-up arrangements'. We believe it should be made explicit that 'support available' should include local or national services provided by statutory, voluntary/community or private sector bodies. Among the most obvious of well-established charities are Bliss (UK's leading charity for babies born premature or sick); TAMBA (UK's leading twins and triplets charity); Scope (for support with disability including cerebral palsy); NCT (UK's largest charity for new parents).
26	Neonatal Nurses Association	Statement 1	As part of the discharge planning and support for families early identification and referral to AHP for early support to help the child achieve their best possible outcomes. Discharge planning should include MDT plans, providing complex families with realistic expectations. As part of the process rooming in with the infant can support the families transition to home and identification of observing the babies cues
27	NHS England	Statement 1	In QS 1 the statement suggests that parents or carers of a pre term baby agree a discharge plan with maternity services, it would be beneficial if this explicitly noted neonatal services as well as maternity services as often the baby is being cared for within the neonatal unit and as such it would be those services coordinating the discharge plan. Although it is noted later in the section "what it means for different audiences" that maternity services includes neonatal services it is not clear in the outset so may be missed by provider organisations.
28	NHS England	Statement 1	The neonatal survey would need to identify the gestational age at birth to reflect the correct kind of discharge planning occurred. Of note the responses and planning for a baby born prior to 28weeks gestation would be different to those for a baby born after 30 weeks gestation. This means that some changes may be required to the Neonatal Survey for use after implementation of this guidance.
29	NHS England	Statement 1	The draft guidance refers to routine postnatal care and support available, as per NICE guidance on postnatal care up to 8 weeks after birth however there does not appear to be any recommendation for care if a baby is discharged after the age of 8 weeks, nor does it make it explicitly clear if in such cases this is a corrected age or an uncorrected age. It is also of note that this guidance is currently being updated as of January 2017.
30	NHS England	Statement 1	It would be useful that the discharge plan should include advice to general practitioners about key developmental milestones that should be observed in the community, so that early review could be requested if general practitioners are concerned.
31	NHS Lanarkshire	Statement 1	This statement will be possible to measure with our existing systems- Discharge planning records, Badger data system.

ID	Stakeholder	Statement number	Comments[1]
32	NHS Lanarkshire	Statement 1	This outcome would be possible to measure prospectively, though at present no parental surveys targeting discharge planning currently exits locally, these can be developed with minimal financial and non-financial implications.
33	Royal College of Nursing	Statement 1	Regarding the discussion of a plan with maternity services - many of these babies will be discharged from neonatal units as there is a varied service provision of transitional care, therefore, this wording should include neonatal services as some fall under children's services not maternity services.
34	Royal College of Nursing	Statement 1	We consider that in many cases this would be difficult to measure as there is no system in place in maternity services which links with the neonatal system of Badgernet where this information would be stored. There would be a need for a resource such as National Neonatal Audit Programme (NNAP) which could truly measure this using a national reporting system whereby services have to justify not achieving this benchmark.
35	Royal College of Occupational Therapists	Statement 1	Occupational therapists play a key role in supporting and facilitating discharge planning and the transition home. Occupational Therapists promote parent confidence and competence in caring for their infant during the neonatal unit admission through to their transition to the home environment They assess the suitability and safety of the environment and advice regarding specialist equipment for those babies with complex needs. However many neonatal units do not have Occupational Therapists as part of their MDT. Evidence of a neonatal units having OT represented in their MDT to support discharge planning for high risk infants could be used a quality measure for this statement. (See recommendations 18 and19 in Occupational therapy in neonatal services and early intervention. Ref: Royal College of Occupational Therapists (2017) Occupational therapy in neonatal services and early intervention: practice guideline. London: RCOT.
36	The Royal College of Speech and Language Therapists	Statement 1	We suggest including a frequently asked questions (FAQ) sheet at the point of discharge.
37	The Royal College of Speech and Language Therapists	Statement 1	The RCSLT do not believe the statement to be clear and consistent in all statements
38	Association of Paediatric Chartered Physiotherapists	Statement 2	The single point of contact offered by a neonatal outreach service will be really valuable for parents and will serve as a good contact for AHPs working with these families in the community.
39	Bliss	Statement 2	Suggest final sentence is amended to: '…provide information and reassurance to parents or carers of a preterm baby having enhanced developmental support, through provision of neonatal outreach services.'

ID	Stakeholder	Statement number	Comments[1]
40	Bliss	Statement 2	Suggest sentence is amended to say: ‘parents or carers of a preterm baby who is having extra support know how to contact the neonatal outreach service if they need someone to speak to.’
41	Bliss	Statement 2	Having a single point of contact is important, however it might be helpful to include that face-to-face meetings or home visits can be set up with the neonatal outreach team to provide support in person. This may be particularly important for feeding issues.
			Suggest amending third sentence to say ‘parents or carers can seek advice and support...’
42	Bliss	Statement 2	Many babies are discharged home from units outside of their network and follow-up therefore takes place a long way from home. We suggest that there should be a joined up process that ensures those babies outside of a network can be followed-up locally (i.e. within their home network).
43	British Association of Perinatal Medicine (BAPM)	Statement 2	This has been written in a similar fashion to Quality Statement 1. The ‘Outcome’ (satisfaction) is completely separate from the process of having a single point of contact. Again, if NICE feels this is important there needs to be a separate question not linked to discharge planning as it currently stands. BAPM agrees with the importance of neonatal outreach facilities in providing a single point of contact, and we strongly support development of robust support for parents in the community. It should be acknowledged that, particularly for the most complex children, the named neonatal and/or paediatric consultant providing ongoing care should be involved in (or at least notified of) such contacts, with opportunity to expedite follow up as appropriate. Such close involvement has potential to reduce unscheduled attendance at acute services.
44	Department of Health and Social Care	Statement 2	Nil return from DHSC Maternity team
45	NCT	Statement 2	This ‘definition’ is very unclear: ‘This [point of contact] could be a telephone helpline, e-mail address, or messaging service. A single point of contact within the neonatal service will be staffed by experts in preterm development. Parents or carers can seek advice from this contact … on issues such as feeding, breathing, crying and sleeping’. Unfortunately, parents reading this are left not knowing if their contact is to be an ‘email address’ or a 24/7 service ‘staffed by experts in preterm development’. There is a huge difference, e.g. if there is an problem with the preterm baby’s breathing (one of the issues given as an example) and parents need help/advice particularly outside daytime working hours. It must be made clearer what support there is and if it is not immediate then what the parents should do instead, e.g. call an ambulance.

ID	Stakeholder	Statement number	Comments[1]
46	Neonatal Nurses Association	Statement 2	A time frame for families? how long under Neonatal care (44 weeks corrected) and a seamless transition to paediatric community care with the identification of a continued point of contact for longer term complex cases.
47	NHS England	Statement 2	There does not appear to be any guidance as to the hours of cover for this service provision nor does it identify an acceptable time frame for response specifically if the service is an email or messaging type service provision.
48	NHS Lanarkshire	Statement 2	This statement will be possible to measure with our existing systems- Discharge planning records, Badger data system.
49	NHS Lanarkshire	Statement 2	This outcome would be possible to measure prospectively, though no parental surveys targeting discharge planning currently exits locally.
50	Royal College of Occupational Therapists	Statement 2	Occupational Therapists possess the skills and experience to staff the single point of contact for outreach services given their skills in parent engagement, parent support, identifying developmental concerns and early intervention. Evidence that neonatal units have occupational therapists represented within the neonatal outreach team could be used as a quality measure for this statement.
51	Royal College of Paediatrics and Child Health	Statement 2	The structure/process need to be locally based and responsive. The team does not have to be a Neonatal outreach. It could be either or a combination of other similar groups with same expertise, like HAH/CCNT or hybrids of. Most babies by the time of discharge are no longer neonates but in the paediatric age bracket
52	The Royal College of Speech and Language Therapists	Statement 2	This could be a telephone helpline, defined e-mail address, or other messaging service. We suggest including a frequently asked questions (FAQ) sheet at the point of discharge and also suggesting changing the word ‘reassurance’ (in rationale) to ‘support’
53	Association of Paediatric Chartered Physiotherapists	Statement 3	There is some discrepancy on page 14 - in the first paragraph (healthcare professionals) it states professionals are either present or available through referral at the 2 face to face follow up visits and the 2 year assessment but in the 3rd paragraph (children born preterm having extra support) it states the visits should be with a doctor and another health professional. On page 15 it also says an AHP should be present at follow up appointments.
54	Association of Paediatric Chartered Physiotherapists	Statement 3	‘At the visits they discuss with parents or carers whether they have any concerns and check for developmental problems and disorders’ This makes reference to the assessments undertaken at the various follow up appointments but makes no recommendations for how they will check for developmental problems i.e. what standardised outcome measures will be used. Given that they state that a therapist should be present during follow up visits to assess development it would make sense for recommendations to be made to ensure national standardisation of assessment.
55	Association of Paediatric Chartered Physiotherapists	Statement 3	Concerns have been raised about the suggested use of PARCA-R as the sole screening tool with no other assessments being specified (e.g. Bayley III). The PARCA-R is reliant on parental report, therefore making it subjective, and prohibitive for those who are non-English speaking. On p15 it says ‘using specific tools’ but doesn't list any - for national comparison it would be sensible for everyone to be using the same standardised assessments although appreciate this is complex.

ID	Stakeholder	Statement number	Comments[1]
56	Association of Paediatric Chartered Physiotherapists	Statement 3	By specifying 2 follow up visits in the first year of life as a minimum, commissioners will (and some already are) see this as an opportunity to reduce current services – many services that already have an established follow up service see the babies at least 3 times in the first year as a minimum, some as many as 5 times in the first year. Despite the proposed tools for early identification, there is concern that only 2 follow up visits may result in a number of infants with mild – moderate neuromotor abnormalities not being picked up in a timely manner when intervention could be the most effective. As follow up time frames suggest follow up appointments between 3 and 5 months and 12 month this means a baby could be seen at 3 months and then not again until a year when neuromotor difficulties may already be well established. We would suggest a change to a minimum of 3 follow up appointments in the first year.
57	Association of Paediatric Chartered Physiotherapists	Statement 3	We request clarification on whether a GMFCS level is required or a GMFM assessment score if CP is identified as 2 year assessment.
58	Bliss	Statement 3	Suggest that the final two sentences which relate to parents or carers are amended to include mention of signposting them to local or national organisations who may be able to offer them practical or emotional support.
59	British Association of Perinatal Medicine (BAPM)	Statement 3	It is well recognised that children do not attend follow-up for a variety of reasons out with clinicians' control, and even with the best systems in place, follow up will never be 100%. For this reason NICE should change the process definitions from "children…. who HAVE a follow-up visit….." to "children…. who ARE OFFERED a follow-up visit….." for all of the intended visits.
60	Department of Health and Social Care	Statement 3	Response from Children, Families and Communities Team: As the extra checks proposed here for health visitors for children born pre-term would be in addition to the five existing universal, mandated visits for all children aged 0-5, the standards, would presumably, if implemented, place an additional burden on health visitor provider organisations? If this is so, but the organisations who respond to your consultation are content, then the Department of Health and Social Care (DHSC) supports publishing the standards. This is on the understanding that they do not represent too much of an additional financial burden on Trusts and other providers. You may also be interested to know that Greater Manchester Combined Authority re running a pilot scheme looking at additional checks. They already use an 8 stage assessment model for health visits. Salford City Council is now piloting a universal Ages and Stages Questionnaire Social-Emotional (SE) assessment check at 18 months – a new sub-stage (4b) for health visit checks, which will promote uptake of a learning offer for two year olds (involving ASQ 3 and SE). This is being undertaken by Children's Centre Workers and is identifying early delay for communication and language and enabling earlier response language interventions.
61	NHS England	Statement 3	This point refers to "specific tools" but it is unclear what these specific tools may be
62	NHS England	Statement 3	The first bullet point of the section pertaining to the assessment at 2 years (corrected age) suggests that if the PARCA-R is not suitable, a suitable alternative parent questionnaire should be used but does not give clarity as to what a suitable alternative might be
63	NHS England	Statement 3	As per comment number 7

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64	NHS Lanarkshire	Statement 3	This statement will be possible to measure with our existing systems- Discharge planning records, Clinical portal clinic booking records system, Badger data system. However, local unit practice prior to NNAP review, provided follow up for preterm babies <28 weeks as well as those born at between 30-36+6 weeks with the risk factors outlined in the draft
65	NHS Lanarkshire	Statement 3	This outcome would be possible to measure prospectively, though no parental surveys targeting discharge planning currently exits locally.
66	NHS Lanarkshire	Statement 3	Current system in place is a 2 year assessment using the Bayley III developmental assessment tool. No service/structure in place to include PARCAR-R. There may be a staff training requirement here for neonatal MDT follow up team.
67	Royal College of Nursing	Statement 3	The use of the Red Book as a source for data collection is not a guaranteed mechanism as this can be unreliable, not completed or sometimes misplaced by parents. The Badgernet system is really the only assured source of data collection.
68	Royal College of Occupational Therapists	Statement 3	In the section 'What the quality statement means for different audiences', occupational therapists are named as part of the MDT under the Health Care Professionals section. The document recommends they are present at the 2 face-to-face follow up visits in the first year and the assessment at 2 years or available through referral. Occupational Therapy services across the country struggle with waiting times which could cause delays for these babies/ children to be seen. Having an occupational therapist as part of the core neonatal MDT team would mean they could access input as required which could then be handed over to community services allowing continuity of care.
69	Royal College of Occupational Therapists	Statement 3	Infants who are considered high risk as a result of prematurity or other health factors may experience ongoing developmental concerns that can impact on their participation in infant and child occupations. See recommendations: 26-31 in Occupational therapy in neonatal services and early intervention. Ref: Royal College of Occupational Therapists (2017) Occupational therapy in neonatal services and early intervention: practice guideline. London: RCOT. Available at: https://www.rcot.co.uk/practice-resources/rcot-publications/downloads/neonatal-services
70	Royal College of Paediatrics and Child Health	Statement 3	Consideration should also be given to babies with severe/profound/recurrent/symptomatic hypoglycaemia https://www.ncbi.nlm.nih.gov/pubmed/23730298 https://www.ncbi.nlm.nih.gov/pubmed/28740482
71	Royal College of Paediatrics and Child Health	Statement 3	Nice quite properly says a minimum of 2 checks in first year. It would be interesting to know if it would be at least as good to have 2 as 3 or 4 routine checks under 1 year, when there are no additional risk factors.
72	The Royal College of Speech and Language Therapists	Statement 3	At each visit professionals should: (RCSLT suggest adding) 'discuss with parents or carers whether they have any concerns about their child's feeding'

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73	University Hospital Southampton NHS Foundation Trust	Statement 3	Here, the PARCA-R is stated as the main tool to screen for developmental problems age 2. The Ages and Stages questionnaire-3 should be specifically added as an equivalent tool since More widely used (and already part of some local FU programmes and community screening programmes), larger flexibility regarding age range (prevents data loss), web-based version available; available in different languages; recommended at age 4 years in this guideline (therefore would be sensible to use same tool at age 2)
74	University Hospital Southampton NHS Foundation Trust	Statement 3	The GMFCS is mentioned as a measure of overall motor function in children with a diagnosis of CP– this should be changed to GMFCS E&R, which covers the correct age range.
75	University Hospital Southampton NHS Foundation Trust	Statement 3	A measure for manual ability in those with a diagnosis of CP should be included, in line with use of GMFCS E&R; e.g. the Manual Ability Classification System (http://www.macs.nu/), this will be particularly important for infants with unilateral brain lesions.
76	University Hospital Southampton NHS Foundation Trust	Statement 3	Here, some more specifics should be stated on information that is clinically relevant and indicators for outcome, should be collected - Current medication (especially antiepileptic, oxygen, bronchodilators) - Information on acute or chronic illness Here, a neurological assessment should be included, using a standardised tool. This will ensure high quality and reliable outcome data and reliable diagnosis of impaired neurological function.
77	Association of Paediatric Chartered Physiotherapists	Statement 4	‘Healthcare professionals’ Further clarification on who would follow-up at 4 yrs would be of benefit – those involved at 4yrs may have never met the family before which may affect parental reporting of issues/concerns. Also given the key part that AHP’s make in all the assessment to date it would seem beneficial to include access to AHP screening if required at this stage. It would also be ideal to extend the full follow up service (ie to 4years) to all those eligible for enhanced developmental surveillance but appreciate this has further cost implications.
78	British and Irish Orthoptic Society	Statement 4	This statement which says “They ensure that orthoptic vision screening has been offered” would be impossible to implement for every child at 4 years of age. This is because orthoptic-led vision screening is offered between 4-5 years of age, typically in school during the reception year, therefore the screening may take place at any stage between 4 years 1 month to 5 years 10 months depending on the time in the school year that screening is offered and the month of birth of the child. Current vision screening data (Academic year 2015/16) collected by the British and Irish Orthoptic Society shows that the mean age at diagnostic test was 4 years 11 months, ranging from 4 yrs 4 months to 5 years 8 months. This data was collated from 33 screening sites (9,684 referred children). The diagnostic test being the first referral appointment for those failing the initial orthoptic-led screening assessment.

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79	British Association of Perinatal Medicine (BAPM)	Statement 4	4 year follow-up is not as yet on BadgerNet. The follow-up for these patients is likely to be by Community/ Local Paediatricians. This will require systems to be put in place to a) alert them to the existence of all of these children and b) to enable them to have access to BadgerNet (I presume this was included so as to enable NDAU and hence NNAP to access the data). Whilst many extreme preterm may already be under Community follow-up there will be some who are not which may pose difficulties in re-engaging with these families if they have already been discharged from neonatal follow-up.
80	NCT	Statement 4	The rationale states: 'Significant problems cannot always be reliably assessed at the 2 year assessment, or problems … may only become evident at this later age. A face-to-face developmental assessment at 4 years allows difficulties to be identified and gives an understanding of overall development'. Unfortunately there remain children who even at 4 years or later do not have a diagnosis and therefore no prognosis to help their parents plan a future life. Such children are common known as SWANs = 'Syndrome Without A Name' and present a particular challenge for families and those supporting them. The QS4 rationale should not imply that all 'difficulties will be identified': instead parents should be (gently) warned that not all problems may achieve a diagnosis or label.
81	NHS Lanarkshire	Statement 4	All aspects of this statement will be hard to achieve with the current local structure in place, because it would entail an extension of current community paediatrics MDT services in terms of staff capacity, clinic facilities or indeed may require the development of a new service/clinic to enable this to be delivered. Currently, neonatal follow up extends to 2 years assessment corrected GA following which , a referral is made to the community paediatric team if further long term input is required or if a developmental disorder is present or suspected.
82	Royal College of Paediatrics and Child Health	Statement 4	A face-to-face assessment that should involve the following an educational or clinical psychologist: They are now a very rare breed in my experience. Most local authorities do not have enough of them / are very sparse in numbers. They need to be specifically commissioned!
83	Royal College of Paediatrics and Child Health	Statement 4	Re 4 year check: it seems very important to include educational professionals in the assessment and plans from an early stage – hearts and minds are important and education staff will have to implement most of the interventions found at that age
84	Royal College of Paediatrics and Child Health	Statement 4	We fail to see why the checks for < 28 weekers at 4 should not be corrected, at least while interpreting the results. After all a child born 3 months prem is still a significant amount younger than their term peers – 1/16 of their age. Those differences are still apparent at A levels.
85	Royal College of Paediatrics and Child Health	Statement 4	No mention is made of allowing children to be placed in the year they would have been born in for summer born children
86	The Royal College of Speech and Language Therapists	Statement 4	We suggest using standardised tests to assess Speech, Language and Communication Needs, such as the Preschool Language Scale-4 Screening Test (PLS 4 Screening Test)
87		Statement 4	The assessment should include as a minimum:

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	The Royal College of Speech and Language Therapists		(RCSLT again, suggest adding) – 'discuss with parents or carers whether they have any concerns about their child's feeding'
88	University Hospital Southampton NHS Foundation Trust	Statement 4	Children born before 28+0 weeks gestation have a developmental assessment at 4 years of age. This measure should be part of assessment of preterm infant outcome; however, it should be noted that this is not yet national standardised practice across the country and there will be a funding and infrastructure cost to implement this standard. Local services will require infrastructure to deliver this. The data collection systems for this FU assessment at age 4 y will need to be standardised and readily accessible for audit (it is not clear within the NICE document which data collection system will be utilised to capture this 4 year check).

Registered stakeholders who submitted comments at consultation

- Association of Paediatric Chartered Physiotherapists
- Bliss
- British Association of Perinatal Medicine
- British and Irish Orthoptic Society
- Department of Health and Social Care
- National Childbirth Trust (NCT)
- Neonatal Nurses Association
- NHS England
- NHS Lanarkshire
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Occupational Therapists

- Royal College of Paediatrics and Child Health
- The Royal College of Speech and Language Therapists
- University Hospital Southampton NHS Foundation Trust