

British Association of Perinatal Medicine

Consultation response form

<p>Page number/ heading</p> <p>Insert page number/ heading or 'general' if comment relates to the full document</p>	<p>Title of document: Neonatal Service Quality Indicators - Standards relating to Structures and Processes supporting Quality and Patient Safety in Neonatal Services</p> <p>Comments: Please insert each new comment in a new row.</p>	<p>Response</p>
<p>Leeds Children's Hospital at LTHT.</p>		
<p>General</p>	<p>Great piece of work that will undoubtedly help service's grow and develop, improving care to our vulnerable client group. Well done.</p>	<p>Thanks</p>
<p>General</p>	<p>Are we missing a whole section about Developmental Culture required on units? From both a quality and safety perspective having a developmentally sound culture and environment is very important for the high risk babies and their long term outcomes. Things like MDT attendance at ward rounds to discuss developmental management strategies, access to the full MDT for individualised developmental care; low level lighting/eye protectors, sound management strategies / ear protectors, reduction in noxious stimuli / quiet times, developmental positioning etc?</p>	<p>Individualised developmental care is a series of patient interventions which, as a package, is still contentious. This document is purely looking at aspects of the structure and running of the whole of the neonatal service which relate to Quality.</p> <p>Whether a unit practices Developmental care could, more appropriately, be a Clinical (as opposed to Service) Quality Indicator.</p>
<p>Page 11 / Network guideline on care pathways for high risk pregnancies and babies</p>	<p>Should there be some guidance/comment about prioritisation of tertiary specialist patients being prioritised over general high risk babies? This would support tertiary units in their pathway development with regional partners and other tertiary centres.</p>	<p>I am not sure exactly what this means. If this refers to guidance relating to prioritising or restricting admissions to certain high risk groups, this is more of an operational issue for individual Networks, and will depend on the population they serve and the number and types of units in the Network.</p>
<p>Page 14 / 2. Parents should be invited to present on consultant ward rounds</p>	<p>Could this go a step further and support the view that parents should not be excluded from their baby's cot side during ward rounds. Individual units should make arrangements to ensure confidentiality, for example, head phones are used on some units.</p>	<p>We have said that parents should be actively invited (as opposed to just not being excluded) when their own baby is being discussed.</p> <p>The parent access measure has been rewritten to</p>

<p>Page 15 / general point for this section</p>	<p>Could we mention ‘unplanned deliveries’ and something about support and information immediately after delivery when the mother may be on the delivery suite for some time whilst the baby is on the NNU. Could read along the lines of, the NNU team should ensure a medic or nurse visits the mother on the delivery suite to update on her baby’s progress and give information on next steps and what to expect over the next few hours.</p>	<p>encourage units to move towards unrestricted access.</p> <p>This is partly covered by measure 8(5) concerning early communication (by implication this should happen regardless of where the parents are). Perhaps this comment is about babies who have a high risk of complications either because they are extremely preterm or because they are very sick early on. Whilst it is entirely appropriate that parents of this group of babies are spoken to very early, this is a level of detail which is perhaps more appropriate for unit/network guidelines rather than as a national Quality Measure.</p>
<p>Page 25 / Specific Neonatal Triggers for Datix reporting</p>	<p>The list of datix triggers may be too inclusive -</p> <p><i>Specific Neonatal Triggers for Datix reporting</i></p> <ul style="list-style-type: none"> • Neonatal death - • HIE grade 2 or 3 in infants > 34 weeks’ gestation • Meconium aspiration syndrome (typical CXR changes and FiO2>30%) <p>We do not feel any of the above list should trigger a datix. HIE is dated by maternity, death may be expected, Meconium aspiration is largely unpreventable.</p> <ul style="list-style-type: none"> • Hypoglycaemia <1mmol/l or symptomatic hypoglycaemia < 2 mmol/l <p>This may be useful but will generate a significant volume of work for unit staff.</p>	<p>The list of triggers is by no means binding. Although HIE may be reported by maternity, having this on the neonatal list is helpful as a failsafe and it is better to double-report than not at all. There is a consensus that all deaths (regardless of whether expected) should be subject to mortality review, and some units (including my own) use Datix as a way of notifying the patient to the review team. Whilst there is no good evidence that MAS is preventable, it is thought to occur in the context of gasping induced by hypoxia and results in serious morbidity, which is why these should, arguably, be reviewed.</p> <p>Symptomatic hypoglycaemia is a serious pathology with implications for later neurodevelopment and should always be investigated to look for avoidable factors. There should not be a large number of babies with a blood sugar level<1mmol/l. These can be dealt with by a senior individual reviewing the case notes for modifiable factors, and units that have a culture of regular meetings to discuss incidents should not find this onerous.</p>
<p>Page 13 / NSQI 6 Family facilities</p>	<ul style="list-style-type: none"> • 24 hour access to nutritious food and drink without charge for the resident carer, and ideally for both parents. This would be unachievable due to a lack of food preparation facilities or free food on units, limited space for expansion and canteen opening times. This would also have a cost implication especially with long stay families and possible implications across children’s services setting unrealistic expectations of parents within other specialties. • access to an overnight bed for the partner to stay by the cot-side with the mother and baby, when appropriate. This would be difficult in most trusts due to space issues. Clinical space is at a premium and ideally used for managing the babies, especially with the growing demand for this service. We would aim to 	<p>Whilst these comments ring true in many units, this is still a standard we should strive towards in the move to becoming more family centred. Units could reasonably be expected to show that they have, at least, considered and tried to address this indicator.</p> <p>This is again consistent with the Bliss Baby Charter and is a standard which neonatal units should strive towards. For the purposes of clarification, this standard is not implying that the parents’ bed should be at the cotside!</p>

	<p>support one resident parent at the cot side but due to space this will be difficult across the full service and unachievable in the Neonatal ICU. We do allow partners to stay on transitional care but only have space for a chair, not a bed. Could this possibly read “access to an overnight bed or suitable alternative at the cot side……. If space allows”?</p> <ul style="list-style-type: none"> <i>financial support, including free parking for partners. This requires clarification. Is the financial support monetary or advice/signposting? It would be helpful to state the requirement for financial advice and signposting on units. Free parking for partners may also need clarification i.e. one permit per family or two? Two would be unachievable and may set expectations across the children’s service creating greater pressure on the parking facilities with associated stress for families that usually accompanies this issue.</i> 	<p>The wording has been changed to make this clear.</p> <p>This is about signposting to local and national agencies providing support –the wording has been changed.</p>
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Michele Upton, Patient Safety Lead, Maternity and Newborn, NHS Improvement
This response is not reflective of NHS Improvement Patient Safety views as the invitation to consult was through BAPM membership however the team would be happy to input to these if helpful.

Although wider NHSI involvement would provide an England only view, given the wealth of work in this area and in maternity in England, the alignment may be timely, opportunistic and serve to strengthen the work BAPM have undertaken in this area.

<p>General</p>	<p>I have responded to the consultation in my capacity as a BAPM member. However I bring insights from my work as Patient Safety Lead for Maternity and Newborns within the NHS Improvement Patient Safety team.</p> <p>In recognition that this BAPM document is intended to be relevant to all 4 countries, there is a significant amount of work underway in England around this issue in maternity. It could be a lost opportunity not to align this programme with relevant wider national activity.</p> <p>Hence the comments below offer encouragement for areas where alignment is possible. If BAPM would find it helpful the Patient Safety Team would be happy to review the document from their perspective, offering a broader view than this individual response.</p> <p>If so please contact through patientsafety.enquiries@nhs.net</p> <p>Michele Upton Michele.upton@nhs.net</p>	
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<p>10 Staff Safety culture:</p>	<p>Because the safety of neonatal services is also dependant on effective MDT working with maternity, suggest the wording is extended to include the involvement of maternity teams. Be aware that culture surveys are being undertaken as part of the Maternity and</p>	<p>A neonatal safety culture survey might well include questions about interaction with maternity teams. This level of detail is probably outwith the remit of this</p>
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	<p>Neonatal Health Safety Collaborative programme.</p> <p>A useful measure of safety culture is an increase in the number of reports made</p>	<p>document.</p> <p>It is likely that a high level of incident reporting implies that staff are bought in to a safety culture. This is a detail of understanding of what constitutes a safety culture which is again probably outwith the remit of this document.</p>
<p>15 -164.</p> <p>Organised and sensitive approach to giving difficult news and to bereavement</p> <p>Guidance on best practice: There should be appropriate facilities and a sensitive approach to giving difficult or bad news and dealing with bereavement. This should be in line with the Bliss Baby Charter (7).</p>	<p>There are newly published tools available to support staff to do this. Suggest adding in something about 'consideration should be given to supporting staff training in giving difficult news and bereavement support, in line with the Bliss Baby Charter and drawing on publications from SANDS and national organisations' (ref the links and documents)</p> <div data-bbox="443 491 504 550" data-label="Image"> </div> <p>MBEM NHS England NHS London.pdf mat-bereavement-mbem-062017.pdf</p> <p>Also suggest the inclusion of how staff provide support to those with 'seldom heard maternity voices'.</p> <p>Range of resources to support staff to do so: http://patientexperiencenetwork.org/resources/reports/work with 'Change People' & Patient Experience Network</p>	<p>Reference has been made to providing support to parents with learning difficulties, referencing this document.</p>
<p>19</p> <p>Guidance on best practice: Guidance on best practice: There should be clear guidance for staff on the approach to reporting of adverse events, and a list of potential triggers for reporting.</p>	<p>Suggest amendment to say: There should be clear guidance for staff on the approach to reporting of adverse events which should follow national guidance. In England this would refer to the Serious Incident Framework (SIF) (ref). https://improvement.nhs.uk/resources/serious-incident-framework/</p> <p>Conscious that this guidance is for England only but other countries may have their own guidance for reference.</p> <p>Using a trigger list is outwith national guidance (in England). Trigger lists can result in only the listed items being reported and do not allow new risks to be identified and learned from. Staff should be encouraged to report any unintended or unexpected incident which could have, or did, lead to harm for one or more patients receiving NHS-funded healthcare.</p> <p>Additionally, it would be more in line with current principles to say that units should</p>	<p>This section has been modified in accordance with these suggestions.</p>

	<p>develop and foster a culture of openness and transparency in reporting potential (near miss) or actual harm so as to ensure learning and prevent reoccurrence. Suggest removing and a list of potential triggers for reporting.</p> <p>Suggest there should be a statement of how learning from reported incidents is fed back to staff for dual purposes of engaging/promoting staff in developing safety culture; staff seeing a purpose in reporting; and most importantly ensuring learning is disseminated.</p>	
<p>19 Timely review of, and response to, adverse events</p>	<p>One month may be adequate for some incidents but there are national time frames in England for SI reporting and investigation. See link above.</p> <p>Some actions may be so significant or require wider input that their actions can't be undertaken within a month. It might be best to reword this in terms of 'an action plan should be developed within a month with clear time frames for completion of each action'.</p> <p>Include that actions implemented should be audited for effectiveness and an ongoing plan for any remedial action taken.</p> <p>Include that serious incidents should be managed in line with statutory Duty of Candour (where relevant).</p>	<p>The wording has been changed.</p> <p>Added.</p> <p>Added.</p>
<p>20 unit Neonatal Mortality Lead</p>	<p>Add Each Baby Counts</p>	<p>Done.</p>
<p>20 Timely review of neonatal deaths</p>	<p>In line with current national guidance which in England is SIF not the PMRT</p> <p>https://improvement.nhs.uk/resources/serious-incident-framework/</p>	<p>Wording changed.</p>
<p>20 Death reviews carried out to standards of Perinatal Mortality Review Tool</p>	<p>The PMRT is a tool not a standard –it will help achieve a better standard but the standard should be in line with the SI Framework</p>	
<p>20 Criteria for Serious Adverse Event Review</p>	<p>We should require criteria to be that of national guidance and not locally developed. This should either be removed or state 'criteria for AER should follow national guidance where this exists such as the SIF in England.</p> <p>Every effort should be made to avoid locally developed criteria for AER</p>	<p>Re-worded.</p>

21 Serious Adverse Event Reviews follow guidance	Must also follow national SIF guidance	Added.
21 Under 'Quality Measures'	Add that AER should include parental/family involvement in the investigation process. Parents may decline involvement but the process should include an invitation for contributing.	NSQI 14 (8) changed to incorporate this.
21 Structure and resource A multi-professional unit Quality Team	As there is a requirement for every trust to nominate a Board level maternity safety champion in England, suggest they are included in this section. Also include the nominated maternity safety midwifery and obstetric champions as key for building relationships with and whom issues of mutual relevance should be shared and explored. This can be stated broadly so that relevant to all countries but refer to England as an example.	Added.
22 A quality report for the next year	Would suggest that this is done in collaboration with maternity team so that issues that rely on maternity changes can be adequately addressed	Comment added.
23 Training for quality and patient safety	These indicators are very broad and are open to local interpretation and variation in standards. Recommend that these should be more explicit and draw on national work.	References added.
25 List of triggers	Reconsider these as necessary or offer as minimum incident set for reporting but with proviso that reporting should be in line with national guidance where <i>any unintended or unexpected incident which could have, or did, lead to harm for one or more patients receiving NHS-funded healthcare</i> should be reported	See above
North West Neonatal Operational Delivery Network		
3	We believe a neonatal ODN manager would have enhanced this team	It is not clear whether this is a reference to the composition of the Steering Group. These are supposed to be professional standards for use in all the UK nations. Any network perspective not taken account of can be reviewed as part of this consultation.
4-6	No reference to Quality Surveillance Programme (formerly National Peer Review Programme). This may lead to confusion and duplication	The Quality Surveillance Programme Quality Indicators were developed in parallel with these Indicators. A sentence has been added to clarify the distinction between these two documents.
12	Action 5 – As this is not in the current specification should it be included in this document? Suggest should only be included if explicit in the new paediatric/neonatal surgical specification (we understand this is in development)	This document is not a service specification, rather a set of professional standards, some of which are aspirational. We would hope that the new specification document will take account of this document.

18 Quality measures 3&4	Suggest as NHS (Specialised Commissioners) not on membership they should be formally asked to advise on these indicators	It is appropriate for BAPM to set these professional standards and for networks to work with commissioners to implement them.
19	Suggest include network role in relation to lessons learned and patient safety	A sentence has been added to indicate this.
20-21	Suggest include network role in relation network approach to the reduction of neonatal mortality (as directed by NHS England)	Added.
22 -23	Suggest reference to national maternity and newborn safety collaborative	Added.
	Bliss	
Front cover / throughout	<p>We are happy to have this co-branded however there are a couple of points within our comments which are non-negotiable to this. In particular changing the phrasing around joint decision making and parents having unrestricted access on the unit. This is so that it is in line with our position.</p> <p>We would have preferred the consultation document going out without our logo because you might get feedback to the contrary, but hopefully we can work through this. As it is being co-branded the team at Bliss have been very particular!</p>	Bliss has agreed to inclusion of their logo to the final, edited document –thank you.
P3	Zoe – has two dots above the ë	Changed.
P4 bullet point 4	Remove 'expect to' from the final point about parents and commissioners having access to information about the performance of neonatal services, to strengthen the sentence.	Changed.
P5 1 st paragraph	<p>The Neonatal Toolkit should be referred to as the <i>Department of Health Toolkit for High Quality Neonatal Care</i> and italicise 'Bliss baby charter' to be in keeping with other standards referenced.</p> <p>To be aware: the <i>All Wales Standards</i> are currently being updated, so the reference to them may need to be updated.</p> <p>To reference the NHS England Quality Surveillance Programme/Peer Review (England Only)</p>	<p>Changed.</p> <p>This can be changed when the update happens.</p> <p>Added at the end of the section "What is the purpose....?"</p>
P6 1 st paragraph	Change the sentence: Quality Improvement work to improve patient and family outcomes to Quality Improvement work to improve baby and family outcomes	Done.
P6 'how should QI be used'	<p>Can these statements be strengthened to make it clear that these Quality Indicators are not 'nice to do's' but that they should become integrated into measuring performance of the service.</p> <p>For example: Parents should have ready access to information on their unit... Organisations should publish comparative data on some measures...</p>	Changes made.
P7 diagram	Change "Family as partners in care" to "Parental Partnership in care"	Changed.

P7 diagram	On the side where “other standards” are stated please include the Bliss Baby Charter	Added.
P8 1 st paragraph	Change family experience to <i>family centred care</i>	This is referring to the names of the domains of Healthcare identified by the Institute for Healthcare Improvement.
P9 Quality measures	In ‘A rolling programme of audit of practice and mechanism for acting on results’ can further detail be added as to what is considered ‘a timely way’ to ensure the quality measure is measurable, and to avoid a wide range of interpretation.	It is difficult to specify how quickly this should be done, because it depends on the type of practice that is being audited which reflects the degree of urgency for action.
P10 Quality measures	<p><u>Regular safety culture</u></p> <ul style="list-style-type: none"> • Suggest making it clear that the safety culture survey should be anonymous • Why was two years chosen as the length of time between surveys? This seems quite long. The SCORE survey system, outlined in ‘Better Culture, Safer Care’ suggests that after the initial survey, a review survey should take place after 9 months to assess the impact of implementing recommendations from the first survey. A time span of two years between surveys may encourage teams to implement changes slowly. <p><u>Action plan in response to last safety culture survey</u></p> <ul style="list-style-type: none"> • The term ‘timely’ is very vague. Bliss would suggest that this is reviewed to prescribe a timeframe on which short, medium and long-term actions be completed so that this quality measure is fully measurable, and reduces the level of interpretation between different units. <p><u>Interactive learning board or equivalent</u></p> <ul style="list-style-type: none"> • “priorities of the service, what is going well and what is not”. Suggest re-wording because “priorities” implies the key areas that will be addressed following feedback/review and not an analysis of “what is going well and what is not”. 	<p>The wording of this section has been changed to take account of these comments.</p> <p>This has been made clearer along the lines suggested.</p> <p>Wording changed as suggested.</p>
P11 Quality Measures	<p><u>Network Guideline on care pathways for high risk pregnancies and babies</u></p> <ul style="list-style-type: none"> • In NSQI11 it states that babies born under 27 weeks should be born in a centre with a NICU onsite. Bliss would suggest referencing this here as ‘there should be network guidelines on optimal location...for pre term babies born at different gestations of 23 weeks and above...; is not very clear. • Parents should be given written and verbal information 	<p>This is merely saying that each network should spell out which units in their network should care for which babies. Reference has been made to the specific guidance for babies <27 weeks gestation in NSQI 11.</p> <p>Added</p>
P12 Quality measures	<p><u>24/7 availability of transport services</u></p> <ul style="list-style-type: none"> • Bliss agrees that there should be 24 hour transport coverage, however, we know many networks in the UK do not currently have the resources for this. Could the guidance on best practice for this QI be expanded to include something like ‘where the neonatal network currently does not operate a 24 hour transfer service, a review should be undertaken to determine what additional resources that are needed, and an action plan put in place which will 	This has been added.

	<p>work towards 24/7 availability as quickly as possible'</p> <p>Action plan for co-location of neonatal surgical units – it should be stated who has oversight for this measure. Or will this be the remit of the Local Maternity System?</p> <p><u>Arrangements for specialist advice and onsite review for complex babies on neonatal units</u></p> <ul style="list-style-type: none"> 'Timely access' to be defined so this indicator can be measurable, and to avoid wide interpretation. <p><u>Multidisciplinary rounds or meetings including neonatal team and paediatric specialists</u></p> <p>=</p> <ul style="list-style-type: none"> it should be clarified how often the 'opportunities' should take place and if there are any specific points of the pathway – in additional to at clinical referral – where it would be sensible for this to happen. <p>It will also be important to consider here how parents are involved in these discussions. There is mention of parent engagement within the rationale but no allusion to it as part of the quality measures.</p> <p><u>Local guidelines.. palliative care</u></p> <ul style="list-style-type: none"> Can we suggest the bereavement care pathway be referenced here, as well as the Together For Short Lives perinatal pathway https://www.sands.org.uk/professionals/projects-improve-bereavement-care/national-bereavement-care-pathway 	<p>Neonatal</p> <p>A comment has been inserted as suggested that the definition of "timeliness" should be discussed and decided locally.</p> <p>Added.</p> <p>Added.</p> <p>Added.</p>
P13 Family Partnership in Care	Understanding the needs of the family and supporting them during their time in the neonatal unit and post discharge	Added
P13 NSQI Quality Indicator	Quality Indicator Neonatal units should provide family facilities to maximise the time they can spend with their baby on the unit and to reduce the stress and financial burden on families	Added
P13 Rationale	The simultaneous major life events of childbirth and health problems in their baby and potentially the mother	Both changed.
P13 Quality Measures	<p>Would suggest reframing this point on travel to read 'travel needs when families have difficulty visiting their baby.' For some families, even a relatively short distance to a local hospital might be difficult if they can't afford public transport costs.</p> <ul style="list-style-type: none"> When discussing access to an overnight bed, this should state that this is separate to rooming-in facilities. When discussing a partner's access to stay overnight, the 'when appropriate' needs to be clearly defined to avoid wide interpretation and some units not allowing partners to stay overnight unless rooming-in in a family room. Change the point surrounding financial support to: 'financial support, including free parking for both parents/carers.' 	<ul style="list-style-type: none"> Changed The wording has been changed to clarify this. Changed

	<ul style="list-style-type: none"> Do we also want to include here any facilities that promote privacy e.g. screens/curtains, expressing rooms, separate rooms for private consultation/breaking bad news? <input type="checkbox"/> shower facilities for resident parents and appropriate storage, free of charge a family room that is comfortably furnished and provides access to relevant hospital and local and national support information 	<ul style="list-style-type: none"> An entry has been added about a room for private consultations Changed Changed
P.13	“families visiting their baby”- suggest rewording as we don’t describe parents as visitors to their baby.	This wording has been changed.
P14 Quality measures	<ol style="list-style-type: none"> Suggest rewording ‘Decisions about changes in care where parents may express a preference should always involve them’ as this does not sound very clear. <ul style="list-style-type: none"> Within point 1, change the first line to read ‘Every effort should be made...’ from ‘An attempt’ <i>Suggest the best practice paragraph for this QI be reviewed. On reading, it does not sound like it is advocating a joint decision making approach. Would suggest that this section draws on wording from Principle 2 of the baby charter which states that ‘decisions are informed by parents, who are encouraged and supported in the decision making process’</i> 	<p>Changed.</p> <p>This has been rewritten.</p>
P14 Quality measures	<ol style="list-style-type: none"> This should be: <p>Parents have 24 hour, unrestricted access - to include all ward rounds and nursing handovers</p> <p><i>Guidance on best practice: Parents should have unrestricted access to the ward and their baby at all times. Parents should be actively encouraged to be present during consultant ward rounds to enable them to understand the care their baby is receiving and contribute to discussions. Parents should not be expected or asked to leave the cotside, this would include ward rounds when other babies are being discussed. This is to ensure cares, skin to skin and bonding can continue during this period.</i></p> <p>This is a non-negotiable point for Bliss; the quality standards should set out best practice - which we know many units are already delivering (including but not exclusively through introducing new models of care such as family integrated care), and it is vital that this is at the heart of parental involvement in their baby’s care.</p> <p>We would also suggest that this measure should be put at the top of the list on this page.</p> 	Two new measures have been introduced to incorporate parent access and patient confidentiality.
P14 Quality measures	<ol style="list-style-type: none"> Parents are.... <p><i>Guidance on best practice: (including partners)</i></p> 	

	<p>They should be encouraged to increase their involvement during their baby's stay, enabling parents to be confident primary carers for their baby.</p> <p>Would suggest that 'taught to carry out basic care' is expanded on to include examples of what this should include, to increase consistency across units.</p>	Examples added.
P.14 Quality measures	5. These should be in line with either the UNICEF Baby Friendly Initiative standards for neonatal units (29) and / or the Bliss Baby Charter (7).	Done
P15 Quality measures	<p>1. Add 'at the site where baby is expected to be cared for, if different to the mother's booking hospital' at the end of the sentence.</p> <p>Consider changing the oversight for this to the Network as noted above that the neonatal unit of admission may not be on the same site as the maternity service. Or will this be the remit of the Local Maternity System?</p>	<p>Done</p> <p>Done</p>
P15 Quality Measures	2. The Welcome pack should also include information about the visiting policy	Done
	<p>4. Suggest adding in key points from the Bliss Baby Charter here as a minimum level for units to provide across facilities and approach</p> <p>There should be a bereavement lead for each unit with responsibility for this area</p>	<p>Bliss Baby Charter referenced, and national Bereavement Care pathway referenced as "under development with web link under NSQI5.</p> <p>Done</p>
P16 Quality Indicator	<p>Include link to the Baby Charter best practice bank</p> <p>Should we also be advising here that Networks should have Network reps at board level representing the views from; preterm, term, multiples and bereaved parents?</p>	<p>Done</p> <p>Have said that consideration should be given to this.</p>
P16 Quality Measures	1. As with the staff survey, Bliss would suggest that two years is too infrequent to survey parent experiences. Parent experiences should be captured and reviewed frequently, with action plans implemented soon after feedback analysis.	This has been changed.
P16 Guidance on Best practice	Suggest rewording and adding addition detail to this section as it is currently the same wording as in the QI at the top of the page. Additional detail could include that it is best practice for feedback on any parent surveys or other feedback mechanism be shared with both staff and families, and that parent feedback is acted on quickly.	Done
P16 Guidance on Best practice	<p>Suggest setting out how this group will be supported in terms of expenses paid, supervision/support, training etc</p> <p>The parent advisory group could also be included in the measures for NSQI 10 on parent involvement in service development.</p>	<p>Done</p> <p>Done</p>
P17 Quality measures	Include details of how units and networks should be ensuring that parents can be involved in shaping service delivery e.g. through paying travel expenses to meetings etc.	Done
P17 NSQI 11	The Neonatal Toolkit should be referred to as the <i>Department of Health Toolkit for High Quality Neonatal Care</i>	Done

P19 Quality measures	Parents should be able to feed in their experience to the review, and should be informed of the outcome.	Added
P21 Quality measures	Point 8 should be reframed to state that parents should be able to inform the review process, if they want to, as well as have information from the review shared with them. Further, the guidance on best practice sentence for this point should be strengthened to say 'serious adverse events and deaths will result in reports which must be shared with the patient's family in formats they feel comfortable with, for example, through a face-to-face meeting.	Added
P21 Quality measures	1. It should be stated how parents will be supported to be on this group, for example through expenses, training and supervision/support. This point is also relevant for other examples throughout the documents such as parent involvement in feedback, and parent involvement in service design and so may benefit from a specific section of the document setting out how parents should be supported to be involved at a unit/network level.	Added
P24 Rationale	A reference is needed to evidence the line 'parents also perceive units that have a significant research programme as being more dedicated to the clinical care of their baby' Can we add in here that units should make information about research and trails readily available to parents	Done Done
	Liz McKechnie Consultant Neonatologist Yorkshire and Humber Education and Guidelines Lead (North), Neonatal ODN.	
Page 11 QSI4	This is an opportunity for BAPM to state that babies born under 28weeks should receive their care in a NICU - can this QSI be bolder than it is?	A standard specifying that babies <27w GA should be delivered in a centre with a NICU (and by implication receive their care in that NICU) is contained under "Other Neonatal Service Standards" in NSQI 11. It would not be appropriate to extend the gestation range without data justifying this.
Page 13 QSI6	Again an opportunity to be bolder - facilities for a parent to stay next to the baby should be available in special care.	NSQI 6 includes a list of parent facilities specified by Bliss in their Baby Charter. It is not clear whether this comment refers to a bed or seating next to the baby.
	Dr Nandiran Ratnavel Joint Clinical Lead: North East North Central London Neonatal Network Director: London Neonatal Transfer Service	
Page 13	Free food, drink, storage, sibling supervision, finance and parking are unrealistic to expect	This is a standard to aspire to if it's not already being achieved, like many of the others.
Page 14	Quality measure 2: this should be at the discretion of the consultant	The group felt that the aspiration should be to have

		unrestricted access for parents, and indicating that individual consultants have discretion about parent access would allow too much discretion to perpetuate practices that were not family-centred.
	Hannah Shore Consultant Neonatologist TPD Simulation for the School of Paediatrics in Yorkshire and Humber	
	Safety culture surveys... Could we offer a sample survey for units to use? E.g. the one issued through the RCPCH SAFE project rather than everyone inventing their own?	This has now been referenced in the text. In the absence of a neonatal-specific survey, we probably cannot specify which one to use.