NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Neonatal jaundice

Date of Quality Standards Advisory Committee post-consultation meeting:
25 November 2013

2 Introduction

The draft quality standard for Neonatal jaundice was made available on the NICE website for a 4-week public consultation period between 3 October and 31 October 2013. 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 10 organisations, which included Royal Colleges, other national organisations, and a regional NHS Board (Scotland).

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 overarching outcomes, 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 appendices 1 and 2.

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. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

Stakeholders were also invited to respond to the following statement specific questions:

3. For draft quality statement 1: should the statement specify when this information should be given – for example, within 24 hours of the birth? Postnatal care (NICE quality standard 37) quality statement 3 says 'Women or main carers of babies are advised, within 24 hours of the birth, of the symptoms and signs of potentially life-threatening conditions in the baby that require emergency treatment'. This includes jaundice within the first 24 hours after birth.

4. For draft quality statement 2: Is the use of transcutaneous bilirubinometers already routine practice?

4 General comments

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

- Draft quality standard may not have covered all key areas (see section 6).

- Concern that the wording used in relation to breastfeeding was not fully supportive and that the introductory paragraph on 'Why this quality standard is needed' might give a negative impression of breastfeeding.
- The quality standard may lead to over-diagnosis of neonatal jaundice and should have more emphasis on prevention.

Consultation comments on data collection

- Structures and systems are not currently available to collect the required data for the quality standard.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Parents or carers of newborn babies are offered a discussion and given written information about neonatal jaundice, including what to look for and who to contact if they are concerned.

Consultation comments

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

- General support for a quality statement on providing information about neonatal jaundice (particularly in relation to identification).
- Need to clarify who parents/carers might be expected to contact and ensure 24/7 access.
- Expand information to include
  - graphics of normal bilirubin changes
  - how to prevent jaundice, including effective feeding.
- Point about breastfeeding should be more positive and supportive.
- Existing NICE patient information factsheet was highlighted.

Consultation question 3

Stakeholders made the following comments in relation to consultation question 3 ('Should the statement specify when this information should be given – for example, within 24 hours of the birth? Postnatal care (NICE quality standard 37) quality

statement 3 says ‘Women or main carers of babies are advised, within 24 hours of the birth, of the symptoms and signs of potentially life-threatening conditions in the baby that require emergency treatment’. This includes jaundice within the first 24 hours after birth'):

- Consensus to include a timeframe in the quality statement.
- Some stakeholders felt that within 24 hours of the birth would be appropriate.
- Others suggested providing the information anytime prior to discharge or in the first 6 hours after birth, such as at the time of the neonatal check.
- Minimising the risk of providing too much information that might then be overlooked should be considered in the context of timing.

5.2 Draft statement 2

Term and near-term babies who develop suspected jaundice more than 24 hours after birth have their bilirubin level measured using a transcutaneous bilirubinometer within 6 hours.

Consultation comments

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

- Some concern about this as a quality statement (including the evidence base), given that the clinical guideline recommendation says ' if a transcutaneous bilirubinometer is not available, measure the serum bilirubin'.
- Staff training (including calibration and decontamination) highlighted, as well as queries about which staff groups would be expected to use a bilirubinometer, noting that postnatal visits may be made by maternity support workers as well as community midwives.
- Source of the 6 hour requirement queried.
- Concern about cost, particularly in respect of the number of meters required to meet the 6 hour requirement 24/7.
- Uncertainty about which are the best devices.
- There are a number of potential barriers for some women in accessing postnatal care.
- 'Develop suspected jaundice' is an inappropriate term.

Consultation question 4

Stakeholders made the following comments in relation to consultation question 4 ('Is the use of transcutaneous bilirubinometers already routine practice?'):

- Use of transcutaneous bilirubinometers is not typically routine practice in the community.
- Cost may be a barrier to implementation.

5.3 Draft statement 3

Babies with hyperbilirubinaemia are started on treatment in accordance with standardised threshold tables or charts that take into account serum bilirubin level, gestational age and postnatal age.

Consultation comments

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

- Support for a statement on standardised treatment thresholds.
- Need to be clearer that this means tools that ensure treatment is started in accordance with NICE guideline thresholds.

5.4 Draft statement 4

Parents or carers of babies receiving single conventional phototherapy have the opportunity to feed and cuddle the baby, and change the baby's nappy, during short breaks in treatment.

Consultation comments

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

- Range of support for the concept, and recognition of parent experience as a valid improvement area, although concern was raised about whether it should be a quality statement. May be difficult to measure.
- Statement should focus on encouraging and supporting parents/carers to respond to the baby's needs, including skin-to-skin contact.
- Needs a greater focus on breastfeeding, including for babies for who short breaks are not clinically recommended.

- Discussion about the length of break, which may be too short for effective breastfeeding but also which parents should understand will prolong overall treatment time.
- Suggestions to review outcome (experience) measures.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Examining the baby for jaundice at every opportunity, especially in the first 72 hours.
- Details of visual inspection.
- Encouraging and supporting continued effective breastfeeding.
- All remaining areas covered by key priorities for implementation in NICE clinical guideline 98, not covered in the draft quality standard:
  - Identifying babies with risk factors and providing additional visual inspection during the first 48 hours.
  - Not relying on visual inspection alone to estimate the bilirubin level in a baby with jaundice.
  - Indications for serum bilirubin measurement (including jaundice in the first 24 hours) and not using icterometers.
  - Babies with raised conjugated bilirubin level.

Appendix 1: Quality standard consultation comments table

Stakeholder key	
DH	Department of Health
NCT	National Childbirth Trust
NHS Direct	NHS Direct
NHS GGC	NHS Glasgow and Clyde
RCGP	Royal College of General Practitioners
RCM	Royal College of Midwives
RCN	Royal College of Nursing
RCOG	Royal College of Obstetricians and Gynaecologists
RCPCH	Royal College of Paediatrics and Child Health
UNICEF BFI	UNICEF UK Baby Friendly Initiative

ID	Stakeholder	Comment on	Comments
1	DH	General	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
2	NCT	General	[Role of parents and carers] Quality standards recognise the important role parents and carers have in supporting babies with neonatal jaundice. Healthcare professionals should ensure that parents and carers are [centrally /closely /fully] involved in the decision-making process about investigations, treatment and care. Anxiety about and treatment for jaundice is one of the areas which reduces parents' confidence. Too often assumptions are made about parents' consent, without sensitive communication of full information.

3	NCT	General	Care should be taken to avoid casting doubt on breastfeeding as the optimum, normal way to feed babies. There is still a lack of confidence in, and support for, physiological breastfeeding in the NHS. NICE guidance needs to be very careful not to exacerbate misconceptions. Misinformation abounds eg Moritz's editorial which states: 'Possible indications for supplemental feeding would be >7% weight loss, jaundice, low urine or stool output, lethargy, fever, agitation, inconsolable crying, feeding difficulties or other evidence of delayed lactogenesis'[1]. It is very important that routine care does not increase parents', often fragile, confidence in breastfeeding. Most women want to breastfeed but a high proportion still stop in the first few days and weeks, contrary to their wishes. It is not considered good practice to ask pregnant women whether they intend to breastfeed, as it is preferable to leave this decision open, if they are undecided, rather than pushing women into making a decision before they hold their babies in their arms. (see UNICEF Baby Friendly Initiative, upheld in NICE Postnatal Care and Maternal and Child nutrition guidance) This applies equally to women within the first few days after the birth if they are not familiar with breastfeeding so asking if they intend to breastfeed exclusively could be interpreted either as pressure to breastfeed or lack of confidence in the mother's ability to exclusively breastfeed. Some hospital and community services have still not achieved even the Baby Friendly Standards which were a minimum referred to in NICE Postnatal care guideline in 2006. [1] Moritz, M. Preventing breastfeeding-associated hypernatraemia: an argument for supplemental feeding Arch Dis Child Fetal Neonatal Ed 2013;0:F1–F2. doi:10.1136/archdischild-2013-303898
4	NCT	General	[Additional outcomes] Parents often receive conflicting advice, which in turn increases anxiety and reduces their confidence in healthcare professionals and their ability to care for their babies, with potential long term consequences. So suggest additional outcomes: Parents are able to understand the reasons for testing and therapy where needed and are involved in decision-making. Parents feel confident in caring for their baby, in accordance with their preferences. Parents feel emotionally supported, so that they can support their baby.
5	RCM	General	The RCM welcomes the opportunity to comment on the draft scope of this quality standard. The comments in this response are based on feedback from midwives who reviewed and responded to the RCM on the draft document.
6	RCM	General	We are disappointed that the extensive guideline has only produced 4 statements in the standard.

7	RCN	General	We agree that although neonatal jaundice is common, kernicterus is rare, with approximately 6 or 7 cases occurring in the UK each year these are tragic as they are preventable.
8	RCN	General	We agree that all healthcare professionals involved in assessing, caring for and treating babies with neonatal jaundice in any setting should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. However the detail as to what healthcare professional would be involved in assessing, caring for and treating babies with neonatal jaundice is missing and so this needs to be clarified and defined. Levels of training will be defined by the level of care giver in line with the FHEQ framework across all settings including children's wards and department's neonatal units, continuing care units, transitional care and domiciliary care. The competencies should be defined at national level with local auditing and monitoring to ensure standards of provision are assured. Consideration needs to be given to the above to support the implementation of this standard.
9	RCN	General	Agree that Healthcare professionals should ensure that parents and carers are involved in the decision-making process about investigations, treatment and care wherever possible. In reality there are often very limited range of investigations, treatment and care and so there may be few choices that parents can choose from.
10	RCOG	General	The answer is yes to both questions on pg4. [QS reflects key areas for improvement and it is possible to collect the data].
11	RCPCH	General	We feel that the following paragraphs are not necessary in this section and may give the wrong impression (especially with regard to the latter paragraph): "Breastfed babies are more likely than formula-fed babies to develop physiological jaundice (that is, jaundice that does not indicate underlying disease)" and "Prolonged jaundice is also more common in breastfed babies, with around 10% still jaundiced at age 1 month".
12	RCPCH	General	The main relevant outcomes (Table 1) should be morbidity rather than mortality based.
13	UNICEF BFI	General	There is concern that the guidelines do not provide proactive, preventative guidance and may lead to over-diagnosis.
14	NHS GGC	Data collection	That is a big "if"- the bottom line is that in many areas they probably aren't, particularly as much of the care of jaundice takes place in the community so the personnel can be quite dispersed.
15	RCM	Data collection	As the systems and structures are not currently in place, we do not consider it possible to effectively collect data for the proposed quality measures.

16	UNICEF BFI	Data collection	What would be the outcome measures that you would expect from collecting the data? Would this add an unnecessary burden to clinical staff? Again, the emphasis should be on prevention.
17	NCT	Statement 1	Information for parents or carers needs to be supported with the provision of clear, user-friendly information on issues such as: Normal changes in bilirubin levels after birth – graphics to illustrate this. Good practice to clear/ avoid jaundice in newborns, eg frequent feeding, sunlight exposure.
18	NCT	Statement 1	The phrase 'reassurance that breastfeeding can usually continue' within the guideline and audit document should be rephrased eg 'Confirmation that staff will help the mother and baby continue to breastfeed.'
19	NCT	Statement 1	There is a lot of information to take in at this point and it would be preferable if fathers or other people who are to be involved in the care of the baby were included in the discussion.
20	NCT	Statement 1	The guidance and Quality Standards assert that information 'should be tailored to the needs and expressed concerns of parents' and 'Care should be taken to avoid causing unnecessary anxiety to parents or carers' which we obviously support, but health professionals need to be trained to listen to parents to understand their concerns and anxieties, rather than assuming that they know in advance.
21	NHS GGC	Statement 1	I agree that this is required, it is auditable by parent interview or questionnaire, or by casenote review. Written guidance is provided by NICE so is readily available.
22	RCGP	Statement 1	This is important as at present there is a lack of standardisation of care of newborn babies with jaundice and their families. There are 3 principal service providers involved: general practice, community midwives and out-of-hours general providers. The information provided currently does not appear to be uniform across all service providers and is not readily accessible for parents at any time of day. There are gaps in the 24hr service where parents are confused about who to contact for advice. This information needs to be provided on the internet as well as being controlled by health care professionals. Patient.co.uk should be considered as a principal resource for hosting this information.
23	RCM	Statement 1	This is clearly an important statement but it would be helpful to include the importance of having written information in local languages. There is so much information to be disseminated, it is important to ensure this is not missed or forgotten by parents.
24	RCN	Statement 1	In principle it is welcomed that parents / carers of newborn babies will be offered information (verbal and written) about neonatal jaundice, informing them on what to look for and who to contact if they are concerned.

25	RCN	Statement 1	This statement reflects the recommendation of the NICE guidelines but it might be wise to indicate that the format should be 'needs appropriate'; the NICE team developed a parent leaflet to support this. The only addition would be the requirement for local details regarding referral. Translation services should be vetted to ensure that when leaflets are translated into other languages their accuracy is assured.
26	RCN	Statement 1	The jaundice a symptom of a cause as a discolouration can develop and deepen insidiously and not be readily apparent to parents. However research evidence suggests that parents are equally able to recognise jaundice with education prior to discharge so this is key.
27	RCN	Statement 1	There are also the risks that the skins of heavily pigmented infants do not make identification easy.
28	RCN	Statement 1	Local health providers will determine the methodology, but the important issue here is that parent have a recognised first line of contact and that this is clearly accessible with a clear referral process in place; that will be measurable. This should be a 24/7 service capable of a rapid response.
29	RCN	Statement 1	We would suggest that maintaining the accuracy of information comes under the quality directorate within each provider organisation
30	RCN	Statement 1	[Equality and diversity considerations] These are covered within the published NICE parent leaflet.
31	RCOG	Statement 1	Suggest including 'all': eg - parents of all newborn babies
32	RCPCH	Statement 1	Will NICE be producing a PIL?
33	RCPCH	Statement 1	We feel that it is important that the conversation is backed up; written information as details of conversations post-delivery may not be remembered in full. Local contacts details imperative.
34	RCPCH	Statement 1	Who would the parents be expected to contact?
35	RCPCH	Statement 1	Why is the term 'usually' used in "…reassurance that breastfeeding can usually continue".
36	UNICEF BFI	Statement 1	It would be helpful to include some information for parents about how to prevent neonatal jaundice. For example, by emphasising the importance of frequent, effective breastfeeding.
37	UNICEF BFI	Statement 1	Any information for parents to be kept as simple as possible eg like the meningitis card.
38	UNICEF BFI	Statement 1	Parents could be encouraged to check that their baby is feeding effectively by monitoring urine and stool output.
39	UNICEF BFI	Statement 1	Staff could reinforce these messages and ensure effective feeding through carrying out formal breastfeeding assessments at planned intervals during the early postnatal period. The revised Baby Friendly standards (http://www.unicef.org.uk/BabyFriendly/Health-Professionals/New-Baby-Friendly-Standards/) require maternity facilities to ensure that breastfeeding assessments are carried out on at least 2 occasions.

40	UNICEF BFI	Statement 1	Page 8, bullets. An extra bullet could be added which describes practices which support effective breastfeeding and therefore effective milk transfer such as skin to skin contact, effective positioning and attachment, frequent, responsive feeding.
41	UNICEF BFI	Statement 1	The final bullet would be clearer if it read: Mothers should be reassured that breastfeeding can continue as this will help the baby's overall wellbeing. Support should be offered to improve attachment and express breastmilk which can be offered to the baby in addition to breastfeeds.
42	NCT	Question 3	For some women this information could be given before the baby is born, for instance if a premature baby, or twins are expected. For most women, within 24 hours of the birth would be appropriate.
43	NHS Direct	Question 3	Yes the statement should specify that the information is given within 24 hours of the birth because: The parents/carers are then aware of what to look out for/actions to be taken at a very early stage If the baby is discharged in the first 24 hours it will ensure it is not missed (however should be part of the discharge package) To maintain consistency across NICE advice as it is stated in Postnatal care (NICE quality standard 37).
44	NHS GGC	Question 3	Hmm, hard to say. It may be better to give the info at discharge home, or if jaundice is detected, rather than in the first 24 hours when there is a risk of information overload and important issues could be overlooked.
45	RCM	Question 3	The statement should specify when the information should be given. As the guideline recommends that information received by parents includes the importance of recognising jaundice in the first 24 hours, this statement should reflect an appropriate time frame for parents to receive the information. This would be most helpful in the first 6 hours, as many women are discharged from hospital at this point.
46	RCN	Question 3	We would suggest that this is introduced as part of the discharge checking procedure.
47	RCOG	Question 3	It would be advisable to provide a time frame – suggest prior to discharge.
48	RCPCH	Question 3	Should also state time frame of within 24 hours of birth as pathological jaundice starts here and it is important to avoid serious morbidity.
49	UNICEF BFI	Question 3	Page 9, timing of giving information Suggest this could be given at the time of the neonatal check and then reinforced prior to transfer home.

50	NCT	Statement 2	Postnatal visits are now so limited that jaundice could easily be missed. In some areas, healthcare assistants or peer supporters undertake some postnatal visiting. In other areas women are expected to go to clinics. This means women who have difficulty accessing transport, either because they have had a caesarean or other procedure which affects their mobility, have other children who need their attention or do not have the money to pay for it, are likely to miss out on postnatal visits (also relevant to equality and diversity considerations).
51	NHS GGC	Statement 2	I have a few issues with this. Firstly it differs from NICE who say “if a transcutaneous bilirubinometer is not available, measure the serum bilirubin”. Whilst many would say that use of transcutaneous bilirubinometer is preferable to blood sampling, I don’t think this is the same as a quality standard.
52	NHS GGC	Statement 2	If it is desired to pursue this as a quality standard then I think it needs to be split into 2 parts- first organisational, ie does the practitioner have access to a transcutaneous bilruniometer, and secondly, if so was it used within 6 hours. That way there is an onus on an organisation to provide the equipment and an onus on the individual to use it.
53	RCGP	Statement 2	It is important to have an accurate measure of bilirubin levels in order to accurately assess the severity of the jaundice. Using a transcutaneous bilirubinometer will ensure that parents get the information back immediately so that a care plan can be formulated quickly. However using point of care testing in the community has considerable problems including calibrating the equipment and ensuring the availability at 24hr/day without incurring a loss of small expensive pieces of equipment.
54	RCGP	Statement 2	Currently there are no universal standards in the time by which a blood bilirubin is taken.
55	RCM	Statement 2	The supporting information refers to health professionals, but much care in the community is undertaken by maternity support workers - will all community midwives and maternity support workers be expected to use a biliruninometer?
56	RCM	Statement 2	Members have also commented on their lack of reliability and have requested to see the relevant evidence reporting that they are superior to professional judgment. They suggest that when staff are experienced and if they have a skin colour gauge it is possible to significantly reduce the number of blood tests babies have done.
57	RCM	Statement 2	Members have commented on the expense and suggested it would be useful if the NICE guideline recommended which are the best machines.
58	RCN	Statement 2	We believe that the NHS should be offering a 24/7 service to families, this needs to be considered as part of this.

59	RCN	Statement 2	The accuracy and availability of these meters and the training of staff in the use of these and the calibration and decontamination requirements is important.
60	RCN	Statement 2	[Audience descriptors] Each organisation needs to determine availability in-line with the expected protocol e.g. it could be that one TCM is kept at the local surgery or indeed that one is issued to each midwife in community. This would also include: -the process to follow if one becomes faulty, for example one per X number of staff, between X number of infants. -the location of equipment if one was to be shared and ease for staff to collect these.
61	RCOG	Statement 2	You cannot develop suspected jaundice. You can only suspect a baby of developing jaundice. Suggest rephrasing ' babies who are suspected to have developed jaundice'
62	RCOG	Statement 2	Training in the use of transcutaneous bilirubinometers. Suggest ' service providers ensure availability and have local protocols, including training, in place'
63	RCPCH	Statement 2	"…Term and near-term babies who develop suspected)", develop suspected is an inappropriate term
64	RCPCH	Statement 2	Use of transcutaneous bilirubinometers should be encouraged as involves less blood taking/pain for the baby and saves midwifery/junior doctor time. If the commissioners are asking for this data this will encourage its use.
65	RCPCH	Statement 2	We feel that the phrase '… develop suspected jaundice' is not an appropriate term.
66	RCPCH	Statement 2	What is the 6 hours based on, with regard to the bilirubin levels being measured? This would mean that every community midwife has to have one. Have these costs been estimated? Otherwise babies will have to come into hospital to be checked which is not ideal.
67	UNICEF BFI	Statement 2	Is more guidance for staff on the use of transcutaneous bilirubinometers required?
68	UNICEF BFI	Statement 2	The initial statement should include that a breastfeeding assessment is carried out alongside bilirubin measurement.
69	NCT	Question 4	I do not believe that transcutaneous bilirubinometers are available to all community midwives.
70	NHS GGC	Question 4	In hospital practice yes, though it is not universal. In the community not yet due to the costs involved.
71	RCM	Question 4	There is considerable variation in practice in the use of transcutaneous bilirubinometers versus the blood tests.
72	RCPCH	Question 4	The use of transcutaneous bilirubinometers may not be standard practice throughout the UK.

73	NHS GGC	Statement 3	Hard to argue with this- should it be specifically the NICE charts or any gestation specific charts?
74	RCGP	Statement 3	Standardisation with regularly updated threshold charts is vital to ensure high quality care across the UK. The introduction of a standard table will reduce the risk of error in interpretation and ensure that training in one area will be consistent with training in another area.
75	RCN	Statement 3	Agree
76	RCN	Statement 3	[Rationale] This is about ensuring that treatment is commenced in line with guidelines…i.e. the measurement is plotted etc
77	RCPCH	Statement 3	Standardised treatment charts will mean that benchmarking of treatment and looking at outcomes will be possible.
78	UNICEF BFI	Statement 3	Page 14, suggest insert parents are supported to feed their baby and respond to their baby's cues for feeding.
79	NCT	Statement 4	All too frequently the use of technology to treat neonatal jaundice is allowed to interfere with the natural processes which facilitate bonding and breastfeeding. This statement seriously undervalues frequent or continuous early contact, skin to skin, between babies and their parents. Early close body contact between the mother and baby helps to regulate the newborn's temperature, energy conservation, acid-base balance, respiration, reduces crying, and supports breastfeeding behaviour[1]. It also provides reassurance, helps to calm babies and empower mothers. The Cochrane review found skin-to-skin contact between a mother and her new baby increases breastfeeding initiation, duration and milk production. Babies interact more with their mothers and it is also possible that they are more likely to have a good early relationship with their mothers, although this is difficult to measure[2]. [1] Winberg J. Mother and newborn baby: mutual regulation of physiology and behavior--a selective review. Dev Psychobiol. 2005;47(3):217-29. [2] Moore ER, Anderson GC, Bergman N, and Dowswell T. Early skin-to-skin contact for mothers and their healthy newborn infants. Cochrane Database of Systematic Reviews 2012, Issue 5. Art. No.: CD003519. DOI: 10.1002/14651858.CD003519.pub3. Available from: https://www.evidence.nhs.uk/nhs-evidence-content/journals-and-databases
80	NCT	Statement 4	We suggest a change to the wording of this statement: Parents or carers of babies receiving single conventional phototherapy are encouraged to feed and cuddle the baby, in skin-to-skin contact if they wish and change the baby's nappy, during short breaks in treatment.

81	NCT	Statement 4	If breaks in phototherapy are not recommended for babies with moderate or high levels of serum bilirubin, mothers who are breastfeeding should be encouraged and supported to express breastmilk and feed their babies expressed breastmilk, while breastfeeding is not possible.
82	NCT	Statement 4	“Feedback from parents or carers on feeling supported to interact with the baby during single conventional phototherapy” This does not reflect the power relationships and knowledge prevalent in many cases. Parents need to know that they should be able to care for their babies, and continue breastfeeding, in order to respond adequately to this.
83	NCT	Statement 4	Additional outcome measure: Feedback from mothers on feeling supported to continue breastfeeding their baby during single conventional phototherapy and multiple phototherapy.
84	NHS GGC	Statement 4	Whilst I’m sure we would all agree that this is something that should be aimed for, I’m not sure that it is a “quality standard”. It is not a priority for implementation from NICE. Also hard to measure.
85	RCGP	Statement 4	Child-parent interaction is vital at this stage of the child’s life for both the welfare of the child and the parents. Currently most of this treatment is only available in central areas which makes further disruption to family life and incurs high transport and parking costs. There is potential to improve the experience for parents in this area. Any disruption to the interaction between a newborn baby and its parents, particularly its mother, can have both physical and emotional consequences for all the family.
86	RCM	Statement 4	This is an important statement. Many of these babies will have gone home and need readmission.
87	RCM	Statement 4	There should be a specific reference to breast feeding mothers here recommending that they should be encouraged to continue with breastfeeding and provided with appropriate support as stated in the full guideline.
88	RCM	Statement 4	It is suggested that the babys time out should be limited to 30 minutes. We are concerned that not only could this impact on bonding but if the mother is breastfeeding it could affect her milk supply by limiting feed and less hind milk could prolong jaundice. It would also be helpful to have a discussion of the use of fibreoptics which can reduce interference in baby bonding time.
89	RCN	Statement 4	Parents and carers need to be informed that the longer the infant has out of therapy the longer therapy will be required. Only time spent exposed to therapy is effective.
90	RCN	Statement 4	There is a need to define ‘short- break’ as 20-30 minutes every 3-4 hours of treatment.

91	RCN	Statement 4	[Definitions] If a short break is defined as 30 minutes this may be shorter than some breastfeed babies particularly with lethargic babies. If this is the case and the infant is lethargic and not feeding then we would suggest combination feeds should be considered i.e. try breastfeeding for 20 minutes and top up with expressed breast milk via naso-gastric tube
92	RCOG	Statement 4	[Rationale] Mentioning that breastfeeding is the 'mother's preference' might subtly imply that breastfeeding is not the anticipated or default method of feeding. Perhaps can be re-worded to imply that artificial feeding might be facilitated during such a break if it is the 'mother's preference' or just mention feeding without specifying how.
93	RCOG	Statement 4	Denominator, should specify those are considered be clinically suitable for breaks (not all babies receiving single phototherapy will be suitable).
94	RCPCH	Statement 4	The mention of enteral feeding and its positive impact on jaundice would be useful here.
95	UNICEF BFI	Statement 4	Page 16, suggest parents are supported to respond to their baby's needs and feed and cuddle their baby.
96	NHS GGC	New statement	I would suggest that any quality standards should mirror the key priorities for implementation in the clinical guideline.
97	NHS GGC	New statement	Key areas for implementation are missing, e.g. the need to look out for babies at increased risk and ensure that they have an extra check.
98	RCM	New statement	We think there should be a further statement on examining the baby at every opportunity. Babies should be examined at every opportunity, especially in the first 72 hours, as recommended in the guideline.
99	RCM	New statement	We think there should be a further statement on details of visual inspection.
100	RCM	New statement	We think there should be a further statement on encouraging and supporting continued breastfeeding
101	RCM	New statement	The full guideline recommends that babies who develop suspected jaundice within the first 24 hours, have serum bilirubin measured. There should be a statement on this in the standard.
102	UNICEF BFI	New statement	We suggest increasing the information about pro-active practices such as skin contact, positioning and attachment, assessment of milk transfer, monitoring output and hand expression and offering breastmilk where needed.

Appendix 2: Quality standard consultation comments table (internal)

ID	NICE team	Comment on	Comments
103	QS	Statement 1	A discussion should be 'had', rather than 'offered'.
104	QS	Statement 2	How certain are we that the use of transcutaneous bilirubinometers is cost-effective?
105	QS	Statement 3	Can the specific variables (serum bilirubin, gestational age and postnatal age) be captured in the definitions section rather than the statement itself?
106	QS	Statement 4	What is current practice in this area - how certain are we that this is an area for improvement?
107	QS	General	In mapping to the NHS Outcomes Framework (p.2), could the QS (in theory) contribute to the outcome on emergency readmissions?