

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Neonatal jaundice

Output: Prioritised quality improvement areas for development.

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1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for neonatal jaundice. It provides the Committee with a basis for discussion and prioritising quality improvement areas for developing quality statements and measures, which will be drafted for public consultation.

Structure

The structure of this briefing paper includes a brief overview of the topic followed by a summary of each of the suggested quality improvement areas followed with supporting information.

Where relevant, guideline recommendations selected from the key development source below are presented to aid the Committee when considering specific aspects for which statements and measures should be considered.

Development source

Unless otherwise stated, the key development sources referenced in this briefing paper are as follow:

- [Neonatal jaundice](#). NICE clinical guideline 98 (2010).
- [Postnatal care](#). NICE clinical guideline 37 (2006).

Where relevant, guideline recommendations from the key development sources are presented alongside each of the suggested areas for quality improvement within the main body of the report.

2 Overview

2.1 *Focus of quality standard*

This quality standard will cover the recognition and management of neonatal jaundice in newborn infants (both term and preterm) from birth to 28 days in primary (including community) and secondary care.

2.2 *Definition*

Jaundice refers to the yellow colouration of the skin and the sclerae (whites of the eyes) caused by the accumulation of bilirubin in the skin and mucous membranes. Jaundice is caused by a raised level of bilirubin in the body, a condition known as hyperbilirubinaemia. Jaundice in the first 24 hours of life can be indicative of underlying disease and requires urgent assessment. For most babies, however,

jaundice is not an indication of an underlying disease, and is generally harmless. Physiological jaundice refers to the common, generally harmless, jaundice seen in many newborn babies in the first weeks of life and for which there is no underlying cause. Prolonged jaundice – that is, jaundice persisting beyond the first 14 days in term babies and more than 21 days in preterm babies – is generally harmless, but can be an indication of serious liver disease.

Jaundice has many possible causes, including blood group incompatibility (most commonly Rhesus or ABO incompatibility), other causes of haemolysis (breaking down of red blood cells), sepsis (infection), liver disease, bruising and metabolic disorders. Deficiency of a particular enzyme, glucose-6-phosphate-dehydrogenase, can cause severe neonatal jaundice. Glucose-6-phosphate-dehydrogenase deficiency is more common in certain ethnic groups and runs in families.

Bilirubin is mainly produced from the breakdown of red blood cells. Red cell breakdown produces unconjugated (or 'indirect') bilirubin. Unconjugated bilirubin is metabolised in the liver to produce conjugated (or 'direct') bilirubin which then passes into the gut and is largely excreted in stool. The terms direct and indirect refer to the way laboratory tests measure the different forms.

In young babies, unconjugated bilirubin can penetrate the membrane that lies between the brain and the blood (the blood–brain barrier). Unconjugated bilirubin is potentially toxic to neural tissue (brain and spinal cord) and entry of unconjugated bilirubin into the brain can cause both short-term and long-term neurological dysfunction (bilirubin encephalopathy). The term kernicterus is used to denote the clinical features of acute or chronic bilirubin encephalopathy. Kernicterus is a lifelong disabling neurological problem with manifestations of cerebral palsy and deafness. The risk of kernicterus is increased in babies with extremely high bilirubin levels. Kernicterus is also known to occur at lower levels of bilirubin in term babies who have risk factors, and in preterm babies.

2.3 *Incidence and prevalence*

Jaundice is one of the most common conditions needing medical attention in newborn babies; approximately 60% of term and 80% of preterm babies develop jaundice in the first week of life. Breastfed babies are more likely than bottle-fed babies to develop physiological jaundice during this time and prolonged jaundice is also seen more commonly in these babies, with around 10% of breastfed babies still jaundiced aged 1 month. Although neonatal jaundice is very common, kernicterus is very rare. There are approximately six to seven cases of kernicterus in the UK every year.

2.4 Management

Clinical recognition and assessment of jaundice can be difficult. This is particularly so when carrying out visual inspections of babies with darker skin. Newborn babies are inspected visually for jaundice, especially in the first few days. Babies with risk factors for developing significant hyperbilirubinaemia (for example gestational age under 38 weeks, previous sibling with neonatal jaundice requiring phototherapy) receive additional inspections.

Babies with suspected or obvious visual jaundice in the first 24 hours have their serum bilirubin checked urgently, monitored and are treated according to the results. They also receive a medical review to exclude pathological causes of jaundice.

Babies who develop visible jaundice after 24 hours have their bilirubin monitored, although this may be done using a transcutaneous bilirubinometer in the first instance (where indicated), before progressing to blood sampling.

Bilirubin results are interpreted using threshold figures and treatment threshold graphs which plot days from birth vs bilirubin level with different thresholds for each gestational age in weeks. Once hyperbilirubinaemia is identified, management involves ongoing monitoring of serum bilirubin and may require phototherapy or, rarely, an exchange transfusion of the blood. Phototherapy involves placing the baby under a lamp emitting light in the blue spectrum. Light of the appropriate wavelength converts bilirubin in the skin to a harmless form that can be excreted in the urine.

Babies with jaundice in the first 24 hours of life, babies with significant hyperbilirubinaemia and babies with prolonged jaundice undergo investigations for underlying disease.

Most babies with neonatal jaundice are managed on postnatal wards and in the community. Treatment with phototherapy or exchange transfusion will require admission to a neonatal unit.

See Appendix 2 for key priority for implementation recommendations from NICE clinical guideline 98 (no key priority for implementation recommendations on neonatal jaundice in NICE clinical guideline 37).

2.5 National Outcome Frameworks

The table below shows the indicators from the outcomes frameworks that the quality standard could contribute to:

- [The NHS outcomes framework 2013/14](#)
- [Improving outcomes and supporting transparency – Part 1: A public health outcomes framework for England, 2013-2016](#)

NHS Outcomes Framework 2013/14	
Domain 1: Preventing people from dying prematurely	<i>Improvement areas</i> Reducing deaths in babies and young children 1.6i. Infant mortality ¹ (PHOF 4.1) ii. Neonatal mortality and stillbirths
Domain 4: Ensuring that people have a positive experience of care	<i>Improvement areas</i> Improving women and their families' experience of maternity services 4.5 women's experience of maternity services
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	<i>Improvement areas</i> Improving the safety of maternity services 5.5 Admission of full-term babies to neonatal care
Public Health Outcomes Framework	
Domain 4: Healthcare public health and preventing premature mortality	Indicators 4.1 Infant mortality

3 Summary of suggestions

3.1 Responses

Seven stakeholders responded to the 2-week engagement exercise (14-29 May), four of which submitted suggestions for quality improvements (the remaining three submitting 'no comment' responses). Suggestions were also provided by two specialist committee members.

Table 1 Summary of suggested quality improvement areas

Stakeholders were asked to suggest up to 5 areas for quality improvement. These have been merged and summarised in the table below for further consideration by the Committee (incorporating stakeholder and specialist committee member suggestions). The full detail of the suggestions is provided in Appendix 3 for information.

¹ Indicator shared with Public Health Outcomes Framework

Suggested area for improvement	Stakeholder
<u>Information and support for parents and carers</u> <ul style="list-style-type: none"> • Information • Breastfeeding support • Parent-baby bonding 	NCT RCM SCM B
<u>Identification of hyperbilirubinaemia</u> <ul style="list-style-type: none"> • Risk factors • Jaundice in the first 24 hours • Visual inspection • Measurement of bilirubin 	NCT RCM SCM A SCM B
<u>Management of hyperbilirubinaemia</u>	SCM B
<u>Assessment for underlying disease</u>	SCM A SCM B BSPGHAN BCHFT

Table 2 Stakeholder details (abbreviations)

The details of stakeholder organisations who submitted suggestions are provided in the table below.

Abbreviation	Full name
BCHFT	The Liver Unit, Birmingham Children's Hospital Foundation Trust
BSPGHAN	British Society of Paediatric Gastroenterology hepatology and nutrition
NCT	National Childbirth Trust
RCM	Royal College of Midwives
RCN ²	Royal College of Nursing
RCOG ²	Royal College of Obstetricians and Gynaecologists
RCPH ²	Royal College of Paediatric and Child Health
SCM(s)	Specialist Committee Member(s) A and B

² Submitted 'no comment' response

4 Suggested improvement area: Information and support for parents and carers

4.1 Summary of suggestions

Information

Stakeholders highlight the importance of reassuring parents and carers, but also note that providing information will support early identification. The need for standards that readily apply in the community is noted, in the context of the increasing numbers of early discharges. Communication with parents and their involvement in decisions about their baby's care is emphasised alongside the need for clear, user-friendly information on jaundice risk, bilirubin trajectories, non-clinical interventions and duration of treatment.

Breastfeeding support

Stakeholders underline a need for adequate and skilled breastfeeding support and advice, with a suggestion for more postnatal visits for breastfeeding mothers. Anxiety about and treatment for jaundice is cited as one of the areas which reduces parents' confidence in breastfeeding and increases formula feeding. Skilled support for breastfeeding including equipment, information and support to express breastmilk when the baby needs phototherapy is also highlighted.

Parent-baby bonding

Stakeholders note the importance of facilitating parent-baby bonding during treatment of neonatal jaundice, suggesting keeping therapy sessions as short as is compatible with effectiveness to facilitate skin-to-skin contact.

4.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee's discussion.

Suggested quality improvement area	NICE guidance recommendation	Description
Information	CG98: 1.1.1 (KPI) 1.3.1 1.4.14 1.4.16	Verbal and written information for parents/carers about neonatal jaundice tailored to their needs and concerns including information on what to look for, what to do, treatment and reassurance.

Breastfeeding support	CG98: 1.2.2 1.3.2 1.3.3 1.4.18 1.4.19 CG37 1.4.19	Adequate support for breastfeeding including advice on frequent feeding and support during phototherapy.
Parent-baby bonding	CG98: 1.4.15 1.4.18	Support for parents during phototherapy including interaction with baby and short breaks for feeding, nappy changing and cuddles.

Information

NICE CG98 - Recommendation (key priority for implementation) 1.1.1 (Information for parents or carers)

Offer parents or carers information about neonatal jaundice that is tailored to their needs and expressed concerns. This information should be provided through verbal discussion backed up by written information. Care should be taken to avoid causing unnecessary anxiety to parents or carers. Information should include:

- factors that influence the development of significant hyperbilirubinaemia
- how to check the baby for jaundice
- what to do if they suspect jaundice
- the importance of recognising jaundice in the first 24 hours and of seeking urgent medical advice
- the importance of checking the baby's nappies for dark urine or pale chalky stools
- the fact that neonatal jaundice is common, and reassurance that it is usually transient and harmless
- reassurance that breastfeeding can usually continue.

NICE CG98 - Recommendation 1.3.1 (Information for parents or carers on treatment)

Offer parents or carers information about treatment for hyperbilirubinaemia, including:

- anticipated duration of treatment
- reassurance that breastfeeding, nappy-changing and cuddles can usually continue.

NICE CG98 - Recommendation 1.4.14 (Information for parents or carers on phototherapy)

Offer parents or carers verbal and written information on phototherapy including all of the following:

- why phototherapy is being considered
- why phototherapy may be needed to treat significant hyperbilirubinaemia
- the possible adverse effects of phototherapy
- the need for eye protection and routine eye care
- reassurance that short breaks for feeding, nappy changing and cuddles will be encouraged
- what might happen if phototherapy fails
- rebound jaundice
- potential long-term adverse effects of phototherapy
- potential impact on breastfeeding and how to minimise this.

NICE CG37 – Recommendation 1.4.16 (Maintaining infant health)

Parents should be advised to contact their healthcare professional if their baby is jaundiced, their jaundice is worsening, or their baby is passing pale stools.

Breastfeeding support

NICE CG98 - Recommendation 1.2.2 (Care for all babies)

Ensure that adequate support is offered to all women who intend to breastfeed exclusively³.

NICE CG98 - Recommendation 1.3.2 (Information for parents or carers on treatment)

Encourage mothers of breastfed babies with jaundice to breastfeed frequently, and to wake the baby for feeds if necessary.

NICE CG98 - Recommendation 1.3.3 (Information for parents or carers on treatment)

Provide lactation/feeding support to breastfeeding mothers whose baby is visibly jaundiced.

NICE CG98 - Recommendation 1.4.18 (Monitoring the baby during phototherapy)

During conventional 'blue light' phototherapy:

- using clinical judgement, encourage short breaks (of up to 30 minutes) for breastfeeding, nappy changing and cuddles

³ Refer to 'Routine postnatal care of women and their babies' (NICE clinical guideline 37) for information on breastfeeding support.

- continue lactation/feeding support
- do not give additional fluids or feeds routinely.

Maternal expressed milk is the additional feed of choice if available, and when additional feeds are indicated.

NICE CG98 - Recommendation 1.4.19 (Monitoring the baby during phototherapy)

During multiple phototherapy:

- do not interrupt phototherapy for feeding but continue administering intravenous/enteral feeds
- continue lactation/feeding support so that breastfeeding can start again when treatment stops

Maternal expressed milk is the additional feed of choice if available, and when additional feeds are indicated.

NICE CG37 – Recommendation 1.4.19 (Maintaining infant health)

The mother of a breastfed baby who has signs of jaundice should be actively encouraged to breastfeed frequently, and the baby awakened to feed if necessary.

Parent-baby bonding

NICE CG98 – Recommendation 1.4.15 (General care of the baby during phototherapy)

During phototherapy:

- place the baby in a supine position unless other clinical conditions prevent this
- ensure treatment is applied to the maximum area of skin
- monitor the baby's temperature and ensure the baby is kept in an environment that will minimise energy expenditure (thermoneutral environment)
- monitor hydration by daily weighing of the baby and assessing wet nappies
- support parents and carers and encourage them to interact with the baby.

NICE CG98 – Recommendation 1.4.18 (Monitoring the baby during phototherapy)

During conventional 'blue light' phototherapy:

- using clinical judgement, encourage short breaks (of up to 30 minutes) for breastfeeding, nappy changing and cuddles
- continue lactation/feeding support
- do not give additional fluids or feeds routinely.

Maternal expressed milk is the additional feed of choice if available, and when additional feeds are indicated.

4.3 Current UK practice

Information

A local prospective audit in 2011 of 48 babies on postnatal wards with jaundice found a lack of information provided to parents about jaundice and management strategies⁴. General feedback from many parents during ward rounds and reviews showed that many did not understand what jaundice was and why it was important for it to be monitored and what treatment was available. 75% of the parents of infants with jaundice received information leaflets on newborn jaundice.

During the period June 2012 to April 2013, the [NICE parent information factsheet on neonatal jaundice](#) was accessed online, on average, 83 times per month (range 115-56). The geographical distribution of this access, or what people used the webpage views for, is unknown.

Breastfeeding support

In 2010, 63% of breastfed babies receiving phototherapy for jaundice received additional feeds in the form of formula, water or glucose while in hospital. It is not known how many of these additional feeds were associated with a lack of breastfeeding support⁵.

Parent-baby bonding

No published studies on current practice were identified for this suggested area for quality improvement.

⁴ NICE Shared Learning Database (2012) [An audit on the investigation and management of neonatal jaundice - Barts Health NHS Trust](#)

⁵ The Information Centre for Health and Social Care (2012) [Infant feeding survey 2010](#)

5 Suggested improvement area: Identification of hyperbilirubinaemia

5.1 Summary of suggestions

Risk factors

Stakeholders note that early review of babies with risk factors is not current practice.

Jaundice in the first 24 hours

It is noted that measurement of bilirubin at the right time and in the right way is crucial in cases of jaundice within the first 24 hours as this is more likely to arise from pathological causes and is associated with higher risk of encephalopathy.

Visual inspection

The importance of skills in visual assessment of the baby, including feeding and other behaviour to be used when the mother and baby have been discharged from hospital is stated.

Measurement of bilirubin

The requirement to measure the bilirubin level in a baby with visible jaundice is cited as the main challenge with implementation of the guideline, given the availability of transcutaneous bilirubinometers is still very patchy around the country. Other stakeholders report inconsistent use of both transcutaneous bilirubinometers and blood tests including unnecessary blood tests in low risk groups. Concern around sending babies back to the hospital from the community for serum bilirubin testing is raised, as this promotes anxiety in new parents, as well as putting newborns at risk of infection. It is reported that testing is available in the community in some areas. Stakeholders also emphasise the need to minimise physical and emotional distress with regard to measurement of bilirubin, by using transcutaneous bilirubinometers, anaesthetic cream and smaller needles to reduce the distress provoked by blood sampling for example.

5.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below in inform the Committee's discussion.

Suggested quality improvement area	NICE guidance recommendation	Description
Risk factors	CG98:	Defined risk factors and additional

	1.2.1 (KPI) 1.2.3 (KPI) 1.2.9 (KPI)	visual inspection for babies with risk factors.
Jaundice in the first 24 hours	CG98: 1.2.10 CG37: 1.4.17	Urgent evaluation of babies with jaundice in first 24 hours of life.
Visual inspection	CG98: 1.2.4 1.2.5 (KPI)	Who should and how to carry out visual inspection.
Measurement of bilirubin	CG98: 1.2.6 (KPI) 1.2.14 1.2.15 (KPI) 1.4.18 1.4.21	For babies older than 24 hours and circumstances for when to use a transcutaneous bilirubinometer and when serum bilirubin is necessary.

Risk factors

NICE CG98 - Recommendation (key priority for implementation) 1.2.1 (Care for all babies)

Identify babies as being more likely to develop significant hyperbilirubinaemia if they have any of the following factors:

- gestational age under 38 weeks
- a previous sibling with neonatal jaundice requiring phototherapy
- mother's intention to breastfeed exclusively
- visible jaundice in the first 24 hours of life.

NICE CG98 - Recommendation (key priority for implementation) 1.2.3 (Care for all babies)

In all babies:

- check whether there are factors associated with an increased likelihood of developing significant hyperbilirubinaemia soon after birth
- examine the baby for jaundice at every opportunity especially in the first 72 hours.

NICE CG98 - Recommendation (key priority for implementation) 1.2.9 (Additional care)

Ensure babies with factors associated with an increased likelihood of developing significant hyperbilirubinaemia receive an additional visual inspection by a healthcare professional during the first 48 hours of life.

Jaundice in the first 24 hours

NICE CG98 - Recommendation 1.2.10 (Urgent additional care for babies with visible jaundice in the first 24 hours)

Measure and record the serum bilirubin level urgently (within 2 hours) in all babies with suspected or obvious jaundice in the first 24 hours of life.

NICE CG37 - Recommendation 1.4.17 (Maintaining infant health)

Babies who develop jaundice within the first 24 hours after birth should be evaluated (emergency action).

Visual inspection

NICE CG98 - Recommendation 1.2.4 (Care for all babies)

Parents, carers and healthcare professionals should all look for jaundice (visual inspection).

NICE CG98 - Recommendation (key priority for implementation) 1.2.5 (Care for all babies)

When looking for jaundice (visual inspection):

- check the naked baby in bright and preferably natural light
- examination of the sclerae, gums and blanched skin is useful across all skin tones.

Measurement of bilirubin

NICE CG98 - Recommendation (key priority for implementation) 1.2.6 (Care for all babies)

Do not rely on visual inspection alone to estimate the bilirubin level in a baby with jaundice.

NICE CG98 - Recommendation 1.2.14 (Care for all babies)

Measure and record the bilirubin level urgently (within 6 hours) in all babies more than 24 hours old with suspected or obvious jaundice.

NICE CG98 - Recommendation (key priority for implementation) 1.2.15 (How to measure the bilirubin level)

When measuring the bilirubin level:

- use a transcutaneous bilirubinometer in babies with a gestational age of 35 weeks or more and postnatal age of more than 24 hours
- if a transcutaneous bilirubinometer is not available, measure the serum bilirubin

- if a transcutaneous bilirubinometer measurement indicates a bilirubin level greater than 250 micromol/litre check the result by measuring the serum bilirubin
- always use serum bilirubin measurement to determine the bilirubin level in babies with jaundice in the first 24 hours of life
- always use serum bilirubin measurement to determine the bilirubin level in babies less than 35 weeks gestational age
- always use serum bilirubin measurement for babies at or above the relevant treatment thresholds for their postnatal age, and for all subsequent measurements
- do not use an icterometer.

NICE CG37 - Recommendation 1.4.18 (Maintaining infant health)

If jaundice develops in babies aged 24 hours and older, its intensity should be monitored and systematically recorded along with the baby's overall well-being with particular regard to hydration and alertness.

NICE CG37 - Recommendation 1.4.21 (Maintaining infant health)

If a baby is significantly jaundiced or appears unwell, evaluation of the serum bilirubin level should be carried out.

5.3 Current UK practice

Risk factors

A local prospective audit in 2011 of 48 babies on postnatal wards with jaundice noted that midwives were not flagging up higher risk babies and that many doctors did not enquire about siblings who suffered with jaundice⁶.

Jaundice in the first 24 hours

This same local audit found 90% compliance with serum bilirubin measurement for infants with jaundice in the first 24 hours of life.

Visual inspection

No published studies on current practice were identified for this suggested area for quality improvement.

Measurement of bilirubin

Prior to publication of NICE clinical guideline 98, it was estimated that between 10% and 30% of babies who appeared visibly jaundiced were having their bilirubin

⁶ NICE Shared Learning Database (2012) [An audit on the investigation and management of neonatal jaundice - Barts Health NHS Trust](#)

measured and that transcutaneous bilirubinometers were in use in several areas to test bilirubin levels at that time⁷. In the 2011 Trust-wide audit, 83% of infants (29/35) with jaundice onset after 24 hours had their bilirubin measured using a transcutaneous bilirubinometer. A regional audit of clinical laboratories in 2011 found 18 out of 28 hospitals used bilirubinometers although only 2 of the 28 laboratories were aware of this⁸.

6 Suggested improvement area: Management of hyperbilirubinaemia

6.1 Summary of suggestions

Stakeholders suggest treatment thresholds and monitoring as a key area for quality improvement, citing variable practice especially with regard to the treatment threshold within the first 24 hours. No comments on phototherapy specifically (see section 4 on information and support).

6.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below in inform the Committee's discussion.

Suggested quality improvement area	NICE guidance recommendation	Description
Treatment thresholds and monitoring	CG98 1.2.11 1.2.13 1.3.4 (KPI) 1.4	Monitoring serum bilirubin for babies with jaundice in the first 24 hours of life, use of threshold table and treatment threshold graphs for all babies, and monitoring and measuring bilirubin thresholds during phototherapy.

NICE CG98 - Recommendation 1.2.11 (Urgent additional care for babies with visible jaundice in the first 24 hours)

Continue to measure the serum bilirubin level every 6 hours for all babies with suspected or obvious jaundice in the first 24 hours of life until the level is both:

- below the treatment threshold
- stable and/or falling.

⁷ [Neonatal jaundice: costing report](#). NICE costing report (2010)

⁸ Aitkenhead H. (2011) Audit of neonatal bilirubin analysis in clinical laboratories in South East England. *Clinical Biochemistry* 44 (7): 520-521.

NICE CG98 - Recommendation 1.2.13 (Urgent additional care for babies with visible jaundice in the first 24 hours)

Interpret bilirubin levels according to the baby's postnatal age in hours and manage hyperbilirubinaemia according to the threshold table and treatment threshold graphs.

NICE CG98 - Recommendation (key priority for implementation) 1.3.4 (How to manage hyperbilirubinaemia)

Use the bilirubin level to determine the management of hyperbilirubinaemia in all babies (see threshold table and treatment threshold graphs).

NICE CG98 - Section 1.4: measuring and monitoring bilirubin thresholds during phototherapy.

[See guideline for full recommendations]

6.3 Current UK practice

Before publication of NICE clinical guideline 98, information on existing charts and guidelines from 140 UK hospitals was analysed to establish the range of opinion regarding thresholds at which phototherapy and exchange transfusion are used⁹. Most units were using individual charts (9% were using formulae for deciding when to start phototherapy) but there was wide variation in the choice of the threshold levels at which treatment was recommended and many charts were confusing, poorly presented, sketchily drawn and lacked proper gridlines or axis labels.

A similar study of information from 48 neonatal units in 2010 found significant variation in threshold for treatment, with only one unit using a separate chart for each gestation (28, 32 and 37 weeks)¹⁰.

During the period June 2012 to April 2013, the [NICE jaundice treatment threshold graphs](#) (see Appendix 1) were accessed online, on average, 2,427 times per month (range 1780-2,705). The geographical distribution of this access, or what people used the webpage views for, is unknown.

⁹ Rennie JM, Seghal A, De A *et al.* Range of UK practice regarding thresholds for phototherapy and exchange transfusion in neonatal hyperbilirubinaemia. *Archives of Disease in Childhood Fetal and Neonatal Edition* 2009; 94: F323-F327.

¹⁰ Arora PK, Mohandas S., Ridout D. *et al.* (2010) Are we under or over treating neonatal jaundice. *Journal of Maternal-Fetal and Neonatal Medicine* 23: 580.

7 Suggested improvement area: Assessment for underlying disease

7.1 Summary of suggestions

Stakeholders highlight the importance of early identification of babies with underlying liver disease, in particular those with biliary atresia and metabolic disorders, although the need not to over-investigate as well as under-investigate is stated. Assessment of stool colour is emphasised, and the need for health professionals as well as parents to check nappies. Awareness about the risk of prolonged bleeding is also noted.

Measurement of conjugated bilirubin is highlighted. Stakeholders note that CG98 does not distinguish sufficiently between jaundice caused by immature liver function and jaundice caused by liver disease. Stakeholders suggest checking blood glucose in all babies with hyperbilirubinaemia in addition to those with prolonged jaundice.

Stakeholders note patchy provision of “walk in” or rapid referral clinics for prolonged jaundice and highlight access to expert diagnosis and treatment for babies with liver disease including prompt referral to expert centres. Stakeholders highlight the difficulty of obtaining uncontaminated urine specimens for culture from babies. There is a suggestion that all babies with prolonged jaundice should have G6PD testing, rather than just high risk ethnic groups to ensure it does not get forgotten. A suggestion to revisit the evidence on urine cultures and G6PD testing is made.

7.2 Selected recommendations from development source

Recommendations from the development source relating to the suggested improvement areas have been provisionally selected and are presented below to inform the Committee’s discussion.

Suggested quality improvement area	NICE guidance recommendation	Description
Assessment for underlying disease	CG98: 1.1.1 (KPI) 1.2.12 1.6.2 1.7.1 1.7.2 (KPI) CG37: 1.4.22	Urgent review for babies <24 hours old, investigations for babies with significant hyperbilirubinaemia and investigations for babies with prolonged jaundice. Also information for parents and carers on checking nappies for dark urine or pale chalky stools.

NICE CG98 - Recommendation (key priority for implementation) 1.1.1 (Information for parents or carers)

Offer parents or carers information about neonatal jaundice that is tailored to their needs and expressed concerns. This information should be provided through verbal discussion backed up by written information. Care should be taken to avoid causing unnecessary anxiety to parents or carers. Information should include:

- factors that influence the development of significant hyperbilirubinaemia
- how to check the baby for jaundice
- what to do if they suspect jaundice
- the importance of recognising jaundice in the first 24 hours and of seeking urgent medical advice
- the importance of checking the baby's nappies for dark urine or pale chalky stools
- the fact that neonatal jaundice is common, and reassurance that it is usually transient and harmless
- reassurance that breastfeeding can usually continue.

NICE CG98 - Recommendation 1.2.12 (Urgent additional care for babies with visible jaundice in the first 24 hours)

Arrange a referral to ensure that an urgent medical review is conducted (as soon as possible and within 6 hours) for babies with suspected or obvious jaundice in the first 24 hours of life to exclude pathological causes of jaundice.

NICE CG98 - Recommendation 1.6.1 (Formal assessment for underlying disease)

In addition to a full clinical examination by a suitably trained healthcare professional, carry out all of the following tests in babies with significant hyperbilirubinaemia as part of an assessment for underlying disease (see threshold table and treatment threshold graphs):

- serum bilirubin (for baseline level to assess response to treatment)
- blood packed cell volume
- blood group (mother and baby)
- DAT (Coombs' test). Interpret the result taking account of the strength of reaction, and whether mother received prophylactic anti-D immunoglobulin during pregnancy.

NICE CG98 - Recommendation 1.6.2 (Formal assessment for underlying disease)

When assessing the baby for underlying disease, consider whether the following tests are clinically indicated:

- full blood count and examination of blood film
- blood glucose-6-phosphate dehydrogenase levels, taking account of ethnic origin
- microbiological cultures of blood, urine and/or cerebrospinal fluid (if infection is suspected).

NICE CG98 - Recommendation 1.7.1 (Care of babies with prolonged jaundice)

In babies with a gestational age of 37 weeks or more with jaundice lasting more than 14 days, and in babies with a gestational age of less than 37 weeks and jaundice lasting more than 21 days:

- look for pale chalky stools and/or dark urine that stains the nappy
- measure the conjugated bilirubin
- carry out a full blood count
- carry out a blood group determination (mother and baby) and DAT (Coombs' test). Interpret the result taking account of the strength of reaction, and whether mother received prophylactic anti-D immunoglobulin during pregnancy.
- carry out a urine culture
- ensure that routine metabolic screening (including screening for congenital hypothyroidism) has been performed.

NICE CG98 - Recommendation (key priority for implementation) 1.7.2 (Care of babies with prolonged jaundice)

Follow expert advice about care for babies with a conjugated bilirubin level greater than 25 micromol/litre because this may indicate serious liver disease.

NICE CG37 - Recommendation 1.4.22 (Maintaining infant health)

If jaundice first develops after 7 days or jaundice remains after 14 days in an otherwise healthy baby and a cause has not already been identified, it should be evaluated (urgent action).

7.3 Current UK practice

A retrospective audit of 50 babies referred to a paediatric department in a local district general hospital for prolonged jaundice¹¹ found that stool colour had been documented for all babies.

Questionnaire results from 102 neonatal units across England and Wales found variation in how conjugated jaundice in neonates is investigated¹². 6 units reported not performing a conjugated jaundice screen. Conjugated bilirubin levels that prompted investigations varied between units with 20 (21%) reporting no definite threshold. 65% performed urine culture and hepatitis serology.

¹¹ Ogundele MO, Halliday J., and Weir P. (2010) Implementation of a prolonged neonatal jaundice protocol supported by electronic software. *Clinical Governance* 15 (3): 179-190.

¹² Tzivnikos C, Narayanan C.S. (2011) Range of nicu practice in England and Wales regarding thresholds for neonatal conjugated hyperbilirubinaemia and relevant investigations. *Acta Paediatrica, International Journal of Paediatrics* 100: 69-70

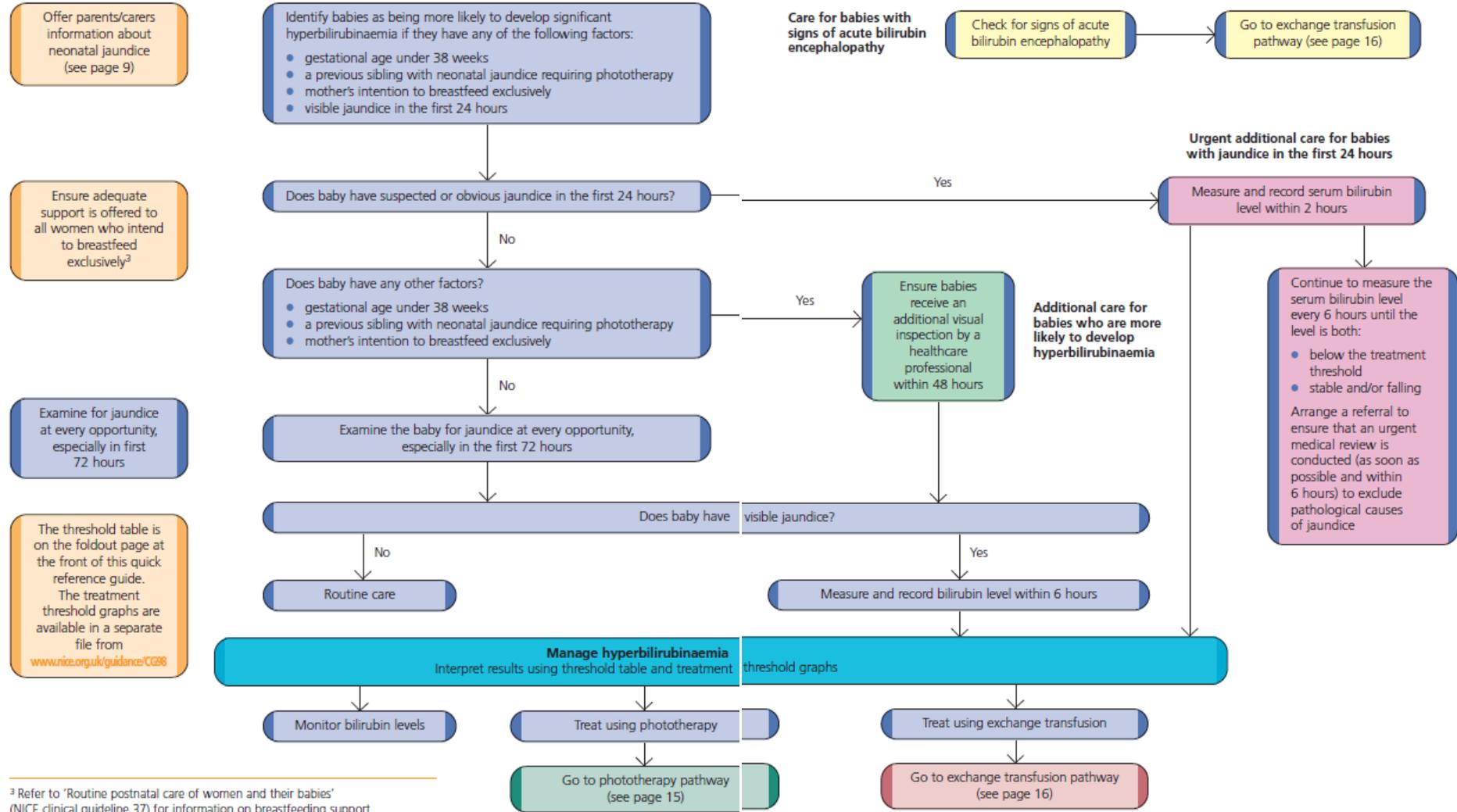
Appendix 1 Additional information

Threshold table

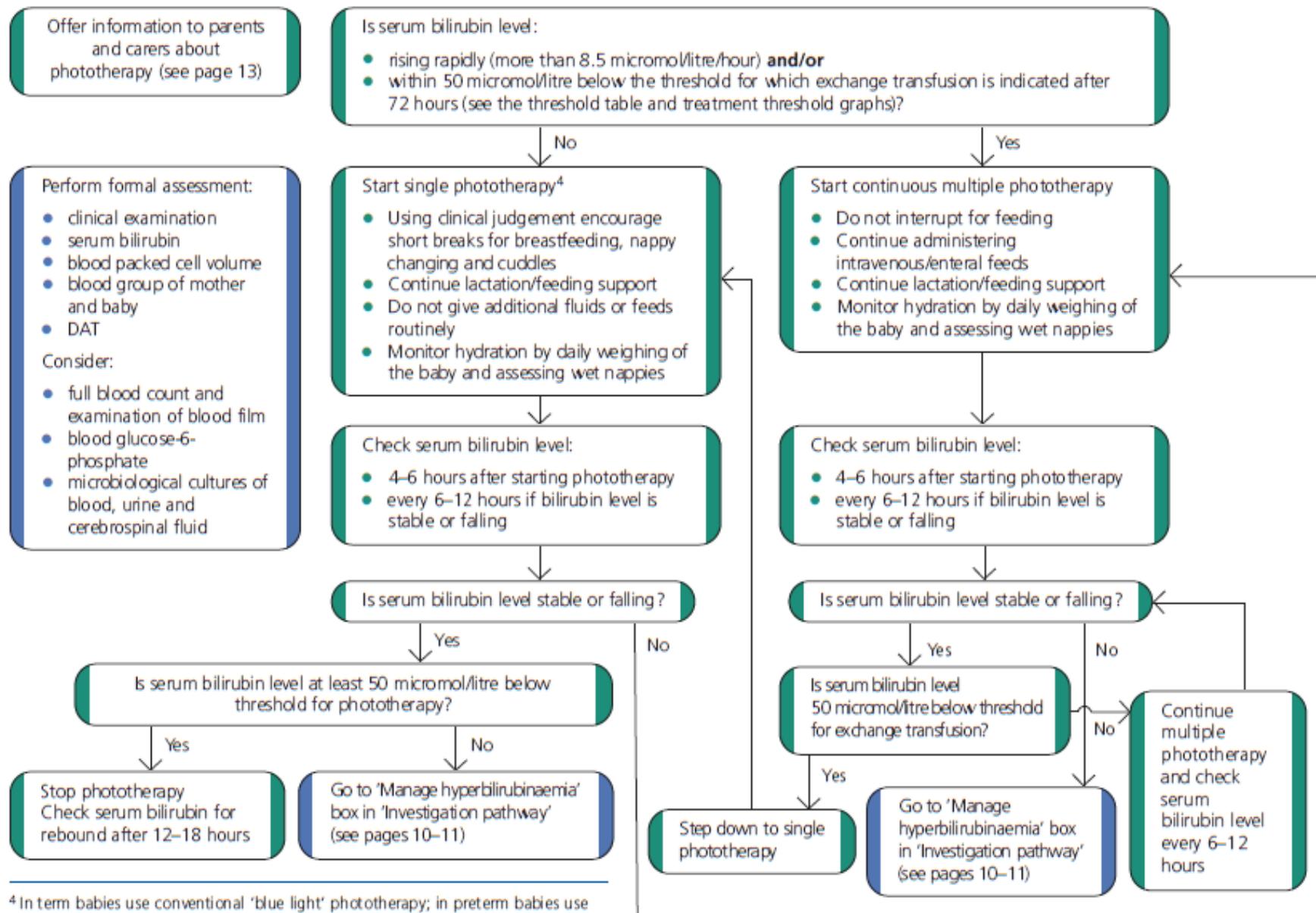
Consensus-based bilirubin thresholds for management of babies 38 weeks or more gestational age with hyperbilirubinaemia

Age (hours)	Bilirubin measurement (micromol/litre)			
0	–	–	> 100	> 100
6	> 100	> 112	> 125	> 150
12	> 100	> 125	> 150	> 200
18	> 100	> 137	> 175	> 250
24	> 100	> 150	> 200	> 300
30	> 112	> 162	> 212	> 350
36	> 125	> 175	> 225	> 400
42	> 137	> 187	> 237	> 450
48	> 150	> 200	> 250	> 450
54	> 162	> 212	> 262	> 450
60	> 175	> 225	> 275	> 450
66	> 187	> 237	> 287	> 450
72	> 200	> 250	> 300	> 450
78	–	> 262	> 312	> 450
84	–	> 275	> 325	> 450
90	–	> 287	> 337	> 450
96+	–	> 300	> 350	> 450
Action	↓	↓	↓	↓
	Repeat bilirubin measurement in 6–12 hours	Consider phototherapy and repeat bilirubin measurement in 6 hours	Start phototherapy	Perform an exchange transfusion unless the bilirubin level falls below threshold while the treatment is being prepared

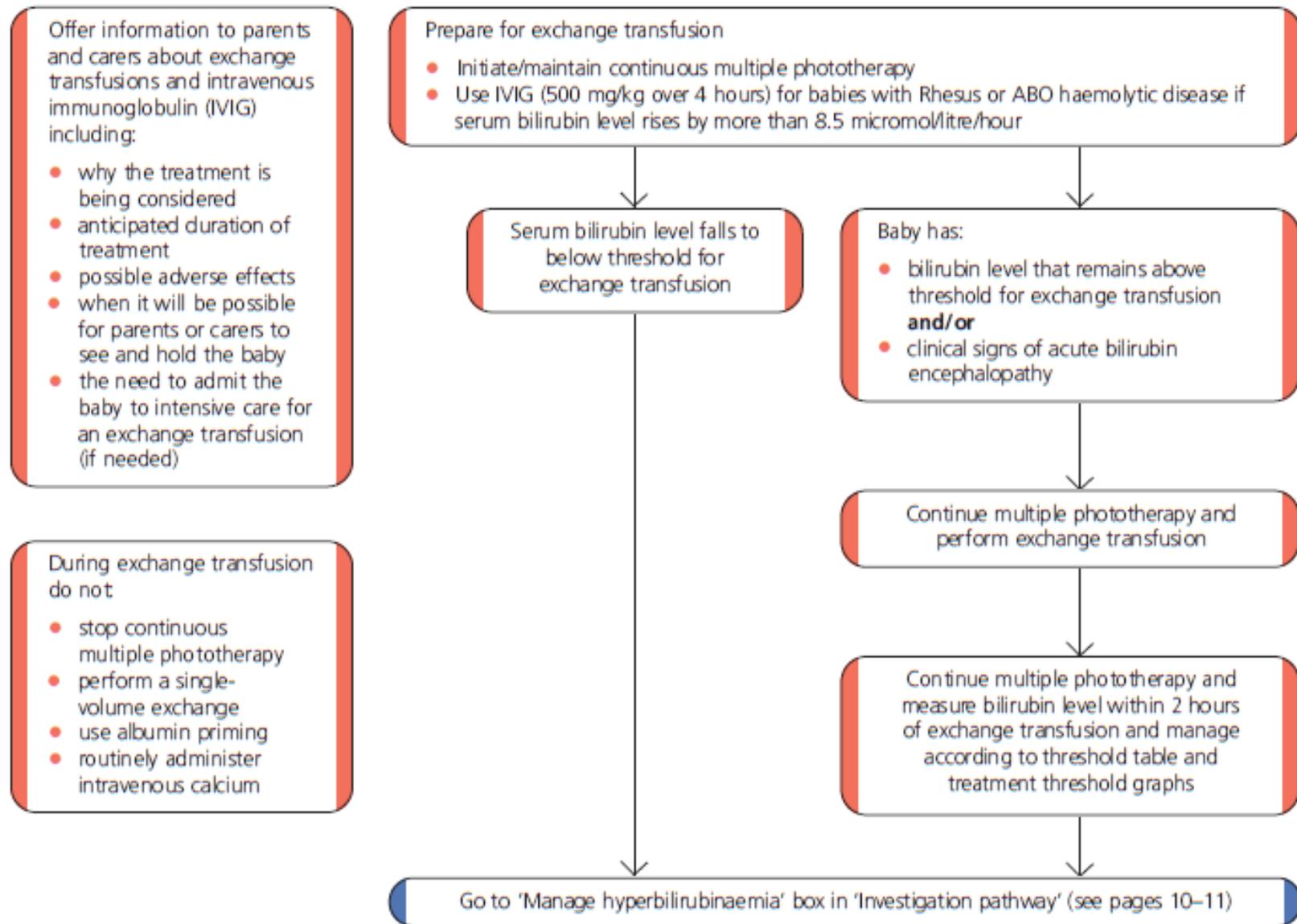
Investigation pathway



Phototherapy pathway



Exchange transfusion pathway

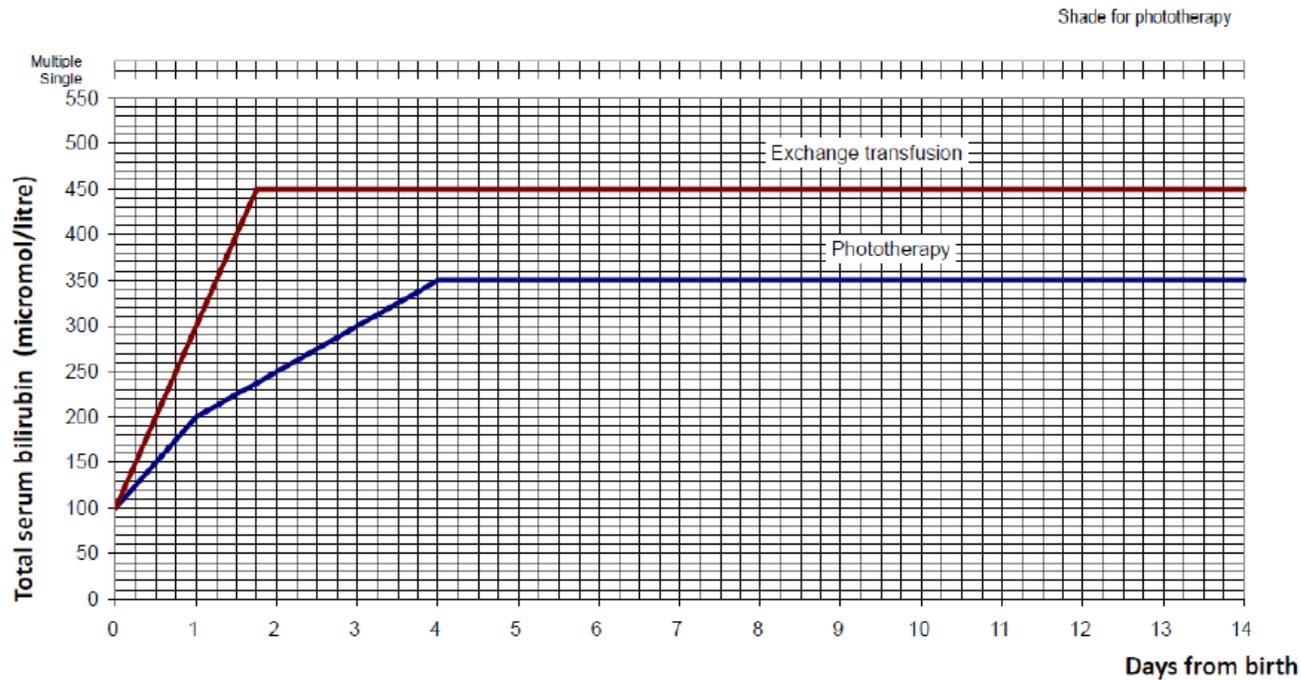


Exchange transfusion

Example of treatment threshold graph for phototherapy and exchange transfusion. Treatment threshold graphs are available for babies of gestational ages from 23 weeks to 38 weeks or more within [NICE clinical guideline 98](#) (Appendix D) and as an [implementation tool](#)

Bilirubin thresholds for phototherapy and exchange transfusion in babies with hyperbilirubinaemia

Baby's name _____ Date of birth _____
 Hospital number _____ Time of birth _____ Direct Antiglobulin Test _____ **>=38 weeks gestation**



Baby's blood group _____ Mother's blood group _____

NHS
 National Institute for
 Health and Clinical Excellence

Appendix 2 Key priorities for implementation recommendations (CG98)

Key priorities for implementation recommendations which have been referred to in the main body of this report are highlighted in grey.

Information

- Offer parents or carers information about neonatal jaundice that is tailored to their needs and expressed concerns. This information should be provided through verbal discussion backed up by written information. Care should be taken to avoid causing unnecessary anxiety to parents or carers. Information should include: – factors that influence the development of significant hyperbilirubinaemia
 - how to check the baby for jaundice
 - what to do if they suspect jaundice
 - the importance of recognising jaundice in the first 24 hours and of seeking urgent medical advice
 - the importance of checking the baby's nappies for dark urine or pale chalky stools
 - the fact that neonatal jaundice is common, and reassurance that it is usually transient and harmless
 - reassurance that breastfeeding can usually continue.

Care for all babies

- Identify babies as being more likely to develop significant hyperbilirubinaemia if they have any of the following factors:
 - gestational age under 38 weeks
 - a previous sibling with neonatal jaundice requiring phototherapy
 - mother's intention to breastfeed exclusively
 - visible jaundice in the first 24 hours of life.
- In all babies:
 - check whether there are factors associated with an increased likelihood of developing significant hyperbilirubinaemia soon after birth
 - examine the baby for jaundice at every opportunity especially in the first 72 hours.
- When looking for jaundice (visual inspection):
 - check the naked baby in bright and preferably natural light
 - examination of the sclerae, gums and blanched skin is useful across all skin tones.

Additional care

- Ensure babies with factors associated with an increased likelihood of developing significant hyperbilirubinaemia receive an additional visual inspection by a healthcare professional during the first 48 hours of life.

Measuring bilirubin in all babies with jaundice

- Do not rely on visual inspection alone to estimate the bilirubin level in a baby with jaundice.

How to measure the bilirubin level

- When measuring the bilirubin level:
 - use a transcutaneous bilirubinometer in babies with a gestational age of 35 weeks or more and postnatal age of more than 24 hours
 - if a transcutaneous bilirubinometer is not available, measure the serum bilirubin
 - if a transcutaneous bilirubinometer measurement indicates a bilirubin level greater than 250 micromol/litre check the result by measuring the serum bilirubin
 - always use serum bilirubin measurement to determine the bilirubin level in babies with jaundice in the first 24 hours of life
 - always use serum bilirubin measurement to determine the bilirubin level in babies less than 35 weeks gestational age
 - always use serum bilirubin measurement for babies at or above the relevant treatment threshold for their postnatal age, and for all subsequent measurements
 - do not use an icterometer.

How to manage hyperbilirubinaemia

- Use the bilirubin level to determine the management of hyperbilirubinaemia in all babies (see threshold table and treatment threshold graphs (Appendix 1)).

Care of babies with prolonged jaundice

- Follow expert advice about care for babies with a conjugated bilirubin level greater than 25 micromol/litre because this may indicate serious liver disease.

Appendix 3 Suggestions from stakeholder engagement exercise

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
001	Specialist Committee Member A	The key problem with the guideline has always been (and still is) implementation of the requirement to measure the bilirubin level in a baby with visible jaundice.	Early review of babies with risk factors is still not happening.	The availability of transcutaneous bilirubinometers is still very patchy around the country, so it has not been possible to audit the real impact of the guideline because it isn't actually happening. There needs to be another national survey of hyperbilirubinaemia and kernicterus in order to know if the numbers have reduced.	
001	Specialist Committee Member A	At the other end of the spectrum there is still patchy provision of "walk in" or rapid referral clinics for prolonged jaundice.			
001	Specialist Committee Member A	Assessment for underlying disease.		The requirement for a urine culture has caused a lot of grief because of the difficulty of obtaining uncontaminated specimens. All babies with prolonged jaundice should have G6PD testing, rather than just high risk ethnic groups. People forget it when it is a subset although it would be a shame to spend the money testing low risk Caucasian babies, I accept.	Maybe we could review that evidence again.
002	Specialist Committee	Information for parents and carers	To make sure that the babies with risk factors are identified early. And also	To provide a consistent approach.	NICE clinical guideline 98 (2010)

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Member B		reassurance is provided when it is appropriate.		
002	Specialist Committee Member B	Measurement of bilirubin level	Inconsistent use of transcutaneous bilirubinometer or blood tests per NICE guideline	Unnecessary blood tests in low risk groups. QS on measurement would standardise the practice.	NICE clinical guideline 98 (2010)
002	Specialist Committee Member B	Measurement of bilirubin level	Standards in when/how to measure is crucial in cases of jaundice within the first 24 hours	More pathological causes and also higher risk of encephalopathy	NICE clinical guideline 98 (2010)
002	Specialist Committee Member B	Treatment thresholds and monitoring	Variable practices especially the treatment threshold within the first 24 hours	To provide a consistent approach.	NICE clinical guideline 98 (2010)
002	Specialist Committee Member B	Investigations for prolonged Jaundice	Variable practices	Not to under or over investigate To identify important diagnoses ASAP.	NICE clinical guideline 98 (2010)
003	British Society of Paediatric Gastroenterology hepatology and nutrition	Early identification of babies with biliary atresia. Will suggest putting in old print or different colour the statement about stool colour. Also emphasising pale stool is a paediatric emergency.	Early surgery before 7 weeks and recent data before 4 weeks improves the outcome of Kasai Porto-enterostomy	These babies as they appear healthy are missed as their jaundice is attributed to physiological causes.	BSPGHAN protocol on management of conjugated jaundice . Children's Liver Disease Foundation parents information.
004	The Royal College of Midwives	Standards that readily apply in the community	In the context of prevalence of early transfer home		HES data document the increase in early transfer home

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					https://catalogue.ic.nhs.uk/publications/hospital/maternity/nhs-mater-eng-2011-2012/nhs-mate-eng-2011-2012-rep.pdf
004	The Royal College of Midwives	Skills in a visual assessment of the baby, including feeding and other behaviour to be used when the mother and baby have been discharged from hospital.	As above, in the context of prevalence of early transfer home there must be standards that apply in the community	Sending babies who are between 25 and 72 hours of age back to the hospital from the community for serum bilirubin testing promotes anxiety in new parents, as well as putting newborns at risk of infection.	Members report an increase in the number of babies that are coming back to hospital for this reason.
004	The Royal College of Midwives	Accessibility of serum bilirubin testing	As above, in the context of prevalence of early transfer home	It would be useful to investigate where, by whom and how testing is done. In some areas testing is available in the home which is obviously a significant benefit to the mother and the baby.	As above, members report an increase in the number of babies that are coming back to hospital for the test. .
004	The Royal College of Midwives	Adequate breast feeding support and advice. A recommendation of more postnatal visits for breastfeeding mothers would be helpful.	The lack of adequate support contributes to the risk for breast fed babies.	The amount of postnatal visits that are undertaken varies - with some units mandating a limited number.	Surveys continue to document that women experience lack of support for breastfeeding http://www.hscic.gov.uk/article/2021/Website-Search?productid=9569&q=infant+feeding+survey&sort=Relevance&size=10&page=1&area=both
005	National Childbirth	Communicating with	The involvement of parents in decisions about their baby's care is a key element of	Parents often receive conflicting advice on these issues, which in turn	Outcome

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Trust	parents	<p>the Specialist Neonatal Care Quality Standard. This needs to be supported with the provision of clear, user-friendly information on issues such as:</p> <ul style="list-style-type: none"> • How much bigger is the risk of NN jaundice in breastfed babies? • Normal changes in bilirubin levels after birth – graphics to illustrate this. • Good practice to clear/ avoid jaundice in newborns, eg frequent feeding, sunlight exposure. • Impact of delayed cord clamping on prevalence of NN jaundice. <p>Duration of treatment if it is necessary</p>	increases anxiety and reduces their confidence in healthcare professionals.	<p>a) Parents are able to understand the reasons for testing and therapy where needed and are involved in decision-making.</p> <p>b) Parents feel confident in caring for their baby, in accordance with their preferences.</p> <p>c) Parents feel emotionally supported, so that they can support their baby.</p>
005	National Childbirth Trust	Facilitation of parent-baby bonding and minimising physical and emotional distress	<p>All too frequently the use of technology to treat NN jaundice is allowed to interfere with the natural processes which facilitate bonding and breastfeeding. We strongly advocate the use of the following:</p> <ul style="list-style-type: none"> • Keeping therapy sessions as short as is compatible with effective treatment to facilitate skin-to-skin contact and kangaroo care. <p>Widespread use of transcutaneous bilirubinometers, anaesthetic cream and smaller needles to reduce the distress</p>		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			provoked by blood sampling.		
005	National Childbirth Trust	Skilled support for breastfeeding	Anxiety about and treatment for jaundice is one of the areas which reduces parents' confidence in breastfeeding and increases formula feeding, with short and long term consequences for mother and baby health and wellbeing. Ensure that adequate support is offered to all women who intend to breastfeed exclusively. including equipment, information and support to express breastmilk when the baby needs phototherapy.	Some hospital and community services have still not achieved even the Baby Friendly Standards which were a minimum referred to in postnatal care guideline in 2006.	Commissioners ensure they commission services that provide timely, personalised support to mothers who are breastfeeding for their social, practical and emotional needs. Support should be appropriate to their family culture, needs and preferences.
006	The Liver Unit, Birmingham Children's Hospital Foundation Trust	Greater emphasis on need for measuring <u>conjugated</u> bilirubin in babies with jaundice persisting more than 14 days e.g. babies who remain jaundiced at 28 days of age must have conjugated bilirubin measured	Access to expert diagnosis and treatment for children with liver disease is important in reducing co-morbidities such as growth faltering, vitamin K deficiency haemorrhage, delayed thyroxine treatment for babies with hypothyroidism and improving access to timely surgery if required.	The present guideline does not sufficiently point to the distinction between jaundice caused by immature liver function and jaundice caused by liver disease – the latter requires evaluation by measuring conjugated bilirubin. Early diagnosis can prevent complications and lead to better outcomes after surgery.	Busfield A et al Vitamin K deficiency bleeding after NICE guidance and withdrawal of Konakion Neonatal: British Paediatric Surveillance Unit study, 2006-2008. Arch Dis Child 2013; 98:41-7 This paper reports 2 yrs surveillance of vitamin K deficiency bleeding; 11 cases identified, 3 had liver disease and 4 had long term morbidity related to intracranial haemorrhage DeRusso PA, Ye W, Shepherd R et al. Growth failure and outcomes in infants with biliary atresia: a report from the biliary atresia research consortium. Hepatology 2007; 46: 1632–8. Davenport M et al Biliary atresia in

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					<p>England and Wales: results of centralisation and new benchmark. J Pediatr Surg 2011;46: 1689-94</p> <p>Kathryn Mary Smart, George Alex, Winita Hardikar. Feeding the child with liver disease. J Gastroenterol Hepatol. 2011;26(5):810-815.</p>
006	The Liver Unit, Birmingham Children's Hospital Foundation Trust	<p>Better signposting for referral to expert centres</p> <p>i.e. babies with conjugated hyperbilirubinaemia (>25micromol/L) to be <u>reviewed promptly by paediatric liver disease specialist i.e. within 14 days</u></p>	<p>Liver disease in infants affects approximately 0.001% live births of which half (50 cases) are caused by biliary atresia.</p> <p>Greater prominence to be given to advice about measuring conjugated bilirubin at day 14 in babies with prolonged jaundice and prompt referral to one of three national paediatric liver units in England.</p>	<p>The present guideline emphasises detection and management of unconjugated hyperbilirubinaemia in first 14 days post nately which reflects the incidence of jaundice at that time (50-80%). However, the serious complication of hyperbilirubinaemia - kernicterus - is rare (0.001% live births or 110 cases per year). Since liver disease has a similar incidence – there is a case for much clearer guidance on referral pathways.</p>	<p>Manning D, Todd P, Maxwell M et al. Prospective surveillance study of severe hyperbilirubinaemia in the newborn in the UK and Ireland. Archives of Disease in Childhood Fetal and Neonatal Edition 2007; 92:(5)F342-F346.</p> <p>Davenport M et al Biliary atresia in England and Wales: results of centralisation and new benchmark. J Pediatr Surg 2011;46: 1689-94</p> <p>Palermo JJ, Joerger S, Turmelle Y, Putnam P, Garbutt J. Neonatal cholestasis: opportunities to increase early detection. Acad Pediatr. 2012 Jul-Aug;12(4):283-7.</p>
006	The Liver Unit, Birmingham Children's Hospital Foundation Trust	Health professionals to check nappies (as well as parents)	Parents may not appreciate the significance of pale coloured stool and the descriptions of stool are often misleading.	<p>The current guideline does not have enough focus on liver disease</p> <p>Parents/health professionals to be aware of the risks of prolonged</p>	Busfield A et al Vitamin K deficiency bleeding after NICE guidance and withdrawal of Konakion Neonatal: British Paediatric Surveillance Unit study, 2006-2008. Arch Dis Child

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				bleeding (eg from heel prick) Stress the necessity to check split bilirubin at all stages (ie how to measure the bilirubin) – this is a simple test for most NHS laboratories	2013; 98:41-7
006	The Liver Unit, Birmingham Children's Hospital Foundation Trust	Advice about care for babies with prolonged jaundice (p6) needs to be expanded.	Galactosemia may present initially with unconjugated hyperbilirubinemia. As well as biliary atresia, metabolic disease presents early with jaundice	Delayed diagnosis leads to worse outcomes eg undetected hypoglycaemia which is a feature of metabolic disorders caused by liver disease such as galactosaemia.	Palermo JJ, Joerger S, Turmelle Y, Putnam P, Garbutt J. Neonatal cholestasis: opportunities to increase early detection. Acad Pediatr. 2012 Jul-Aug;12(4):283-7. <u>Leonard JV, Morris AA.</u> Diagnosis and early management of inborn errors of metabolism presenting around the time of birth. Acta Paediatr. 2006 Jan;95(1):6-14.
006	The Liver Unit, Birmingham Children's Hospital Foundation Trust	Check blood glucose in all babies with hyperbilirubinaemia as well as those with prolonged jaundice	Undetected hypoglycaemia is a feature of metabolic disorders caused by liver disease such as galactosaemia and mitochondrial disorders	Measuring blood glucose is a simple cot- side test which can be carried out in the community as well as in hospital	Fellman V, Kotarsky H. Mitochondrial hepatopathies in the newborn period. Semin Fetal Neonatal Med. 2011 Aug;16(4):222-8. doi: 10.1016/j.siny.2011.05.002. Epub 2011 Jun 15. Mayatepek E, Hoffmann B, Meissner T. Inborn errors of carbohydrate metabolism. Best Pract Res Clin Gastroenterol. 2010 Oct;24(5):607-

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					18. doi: 10.1016/j.bpg.2010.07.012.
007	Royal College of Obstetricians and Gynaecologists (RCOG)	(Submitted "no comment" response)			
008	Royal College of Nursing	(Submitted "no comment" response)			
009	Royal College of Paediatric and Child Health	(Submitted "no comment" response)			