Neonatal jaundice NICE quality standard

Draft for consultation

October 2013

Introduction

This quality standard covers the recognition and management of neonatal jaundice in newborn babies (both term and preterm) from birth to 28 days in primary care (including community care) and secondary care. It does not cover babies with jaundice who need surgery to correct the underlying cause, or the management of conjugated hyperbilirubinaemia in babies. For more information see the topic overview.

Why this quality standard is needed

Jaundice refers to the yellow colouration of the skin and the whites of the eyes caused by a raised level of bilirubin (hyperbilirubinaemia). Jaundice is one of the most common conditions needing medical attention in newborn babies; approximately 60% of term (gestational age of 37 weeks or more) and 80% of preterm babies develop jaundice in the first week of life. Breastfed babies are more likely than formula-fed babies to develop physiological jaundice (that is, jaundice that does not indicate underlying disease). Prolonged jaundice is also more common in breastfed babies, with around 10% still jaundiced at age 1 month¹.

Jaundice in the first 24 hours of life can indicate underlying disease and needs urgent assessment. However, for most babies jaundice is not an indication of underlying disease and is generally harmless, particularly when it develops after the first 24 hours of life. Prolonged jaundice is also generally harmless, although it can be an indication of serious liver disease. Even if there is no underlying disease, unconjugated bilirubin, which is potentially toxic to neural tissue, can penetrate the blood–brain barrier. This can cause both short-term and long-term neurological

¹ Neonatal jaundice. NICE clinical guideline 98 (2010).

dysfunction, known as bilirubin encephalopathy or kernicterus. The risk of kernicterus is increased in babies with particularly high bilirubin levels and for certain groups, such as preterm babies. Although neonatal jaundice is common, kernicterus is rare, with approximately 6 or 7 cases occurring in the UK each year.

How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measureable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 2 outcomes frameworks published by the Department of Health:

- NHS Outcomes Framework 2013/14
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, Part 1 and Part 1A.

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS Outcomes Framework 2013/14

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	Improvement areas
	Reducing deaths in babies and young children
	1.6i. Infant mortality*
	1.6ii. Neonatal mortality and stillbirths
4 Ensuring that people have a positive experience of care	Improvement areas
	Improving women and their families' experience of maternity services
	4.5 Women's experience of maternity services
5 Treating and caring for people in a safe environment and protecting them from avoidable harm	Improvement areas
	Improving the safety of maternity services
	5.5 Admission of full-term babies to neonatal care
Alignment across the health and social care system	
*Indicator shared with Public Health Outcomes Framework (PHOF)	

Table 2 Public health outcomes framework for England, 2013–2016

Domain	Objectives and indicators
4 Healthcare public health and	Objective
preventing premature mortality	Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities <i>Indicators</i>
	4.1 Infant mortality

Coordinated services

The quality standard for neonatal jaundice specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole neonatal jaundice care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to babies with neonatal jaundice in all settings.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality neonatal jaundice service are listed in 'Related quality standards'.

Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. 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.

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 involved in the decision-making process about investigations, treatment and care.

List of quality statements

<u>Statement 1</u>. 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.

<u>Statement 2</u>. 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.

<u>Statement 3</u>. 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.

<u>Statement 4</u>. 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.

Questions for consultation

Questions about the quality standard

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

Question 2 If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

Questions about the individual quality statements

Question 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) <u>quality statement 3</u> 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.

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

Quality statement 1: Information for parents or carers

Quality statement

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.

Rationale

Early identification of neonatal jaundice is essential to ensure that babies receive appropriate treatment for either underlying disease or hyperbilirubinaemia caused by physiological jaundice (that is, jaundice that does not indicate underlying disease), in order to prevent complications and achieve the best clinical outcomes. Advising parents or carers about what to look for and when to contact a healthcare professional will help to ensure rapid access to treatment if needed. This is particularly important in the context of early discharge from maternity units. Giving parents or carers information about neonatal jaundice will also reassure them that it is common, and usually transient and harmless, which will reduce their anxiety if their baby does develop jaundice. Parents or carers of newborn babies receive a large amount of information, which is why a discussion, in addition to written information, is important.

Quality measures

Structure

Evidence of local arrangements to ensure that 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.

Data source: Local data collection.

Process

Proportion of newborn babies whose parents or carers have a discussion and receive written information about neonatal jaundice, including what to look for and who to contact if they are concerned.

Numerator – the number of babies in the denominator whose parents or carers have a discussion and receive written information about neonatal jaundice, including what to look for and who to contact if they are concerned.

Denominator – the number of newborn babies.

Data source: Local data collection. Contained within NICE CG98 audit support criterion 14.

What the quality statement means for service providers, healthcare professionals and commissioners

Service providers ensure the availability of written information on neonatal jaundice (including what to look for and who parents or carers should contact) and ensure that healthcare professionals understand and act on the need to discuss this with parents or carers of newborn babies.

Healthcare professionals ensure that they offer to discuss neonatal jaundice with parents or carers of newborn babies and give them written information, including what to look for and who to contact if they are concerned.

Commissioners ensure that they commission services from providers that can demonstrate written information on neonatal jaundice is available and whose healthcare professionals discuss this with parents or carers of newborn babies, including what to look for and who to contact if they are concerned.

What the quality statement means for patients and carers

Parents or carers of newborn babies have the chance to talk with healthcare professionals and are given written information about jaundice. This includes information about what signs and symptoms to look for, as well as who to contact if they are concerned.

Source guidance

- Neonatal jaundice (NICE clinical guideline 98), recommendation <u>1.1.1</u> (key priority for implementation).
- Postnatal care (NICE clinical guideline 37), recommendation <u>1.4.16</u>.

Definitions of terms used in this quality statement

Information about neonatal jaundice

Information about neonatal jaundice should be tailored to the needs and expressed concerns of parents or carers of newborn babies. The 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 (signs and symptoms to look for):
 - check the naked baby in bright and preferably natural light
 - note that examination of the sclerae, gums and blanched skin is useful across
 all skin tones
- who to contact if they suspect jaundice, jaundice is getting worse, or their baby is passing pale chalky stools or dark urine
- the importance of recognising jaundice in the first 24 hours and of seeking urgent medical advice
- the fact that neonatal jaundice is common, and reassurance that it is usually transient and harmless
- reassurance that breastfeeding can usually continue.

[Adapted from Postnatal care (NICE clinical guideline 37) recommendation <u>1.4.16</u>, Neonatal jaundice (NICE clinical guideline 98) recommendations <u>1.1.1</u> (key priority for implementation) and <u>1.2.5</u>, and Postnatal care (NICE quality standard 37) <u>statement 3</u>.]

Equality and diversity considerations

Information about neonatal jaundice should be accessible to parents or carers with additional needs such as physical, sensory or learning disabilities, and to parents or carers who do not speak or read English. Parents or carers of babies with neonatal jaundice in any setting should have access to an interpreter or advocate if needed.

Extra support with visual checks for jaundice in babies and checking nappies for pale stools or dark urine should be provided to parents or carers with sight impairments.

It may be difficult to recognise jaundice in some babies with dark skin tones. The definition of how to check the baby for jaundice is written to be useful across all skin tones: examination of the sclerae, gums and blanched skin in bright (preferably natural) light.

Question for consultation

Should the statement specify when this information should be given – for example, within 24 hours of the birth? Postnatal care (NICE quality standard 37) <u>quality statement 3</u> 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.

Quality statement 2: Measurement of bilirubin level

Quality statement

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.

Rationale

Transcutaneous bilirubin measurements help to assess the degree of jaundice. They are more accurate than visual inspection and are non-invasive. Using this technique will help to avoid unnecessary serum bilirubin tests (in cases where the measured bilirubin level is below the level requiring a serum bilirubin check) and so reduce distress caused by blood sampling. Because serum bilirubin testing is not always available in the community, using bilirubinometers will also avoid unnecessary transfers to hospital, which will reduce anxiety in new parents and avoid problems such as disruption of feeding. Immediate results will also be reassuring to new parents. Measuring bilirubin within 6 hours of the baby developing suspected jaundice will ensure that babies who need further tests or treatment get this as soon as possible. Because transcutaneous bilirubinometers are not as accurate as serum bilirubin testing, they are not suitable for preterm babies born before 35 weeks of pregnancy or for babies with suspected jaundice in the first 24 hours after birth.

Quality measures

Structure

Evidence of local arrangements to ensure that 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.

Data source: Local data collection.

Process

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

Numerator – the number of babies in the denominator having their bilirubin level measured using a transcutaneous bilirubinometer within 6 hours.

Denominator – the number of term and near-term babies developing suspected jaundice more than 24 hours after birth.

Data source: Local data collection. Contained within NICE CG98 audit support criteria 8 and 9.

What the quality statement means for service providers, healthcare professionals and commissioners

Service providers ensure adequate availability of transcutaneous bilirubinometers and have local protocols in place that enable healthcare professionals to measure the bilirubin levels of term and near-term babies who develop suspected jaundice more than 24 hours after birth within 6 hours.

Healthcare professionals ensure that they measure the bilirubin levels of term and near-term babies who develop suspected jaundice more than 24 hours after birth using a transcutaneous bilirubinometer within 6 hours.

Commissioners ensure that they commission services with adequate availability of transcutaneous bilirubinometers for healthcare professionals to measure the bilirubin levels of term and near-term babies who develop suspected jaundice more than 24 hours after birth within 6 hours.

What the quality statement means for patients and carers

Babies born at or after 35 weeks of pregnancy who show signs of possible jaundice starting more than 24 hours after birth have their bilirubin level measured using a special hand-held device placed briefly on the skin (known as a 'bilirubinometer') within 6 hours.

Source guidance

Neonatal jaundice (NICE clinical guideline 98), recommendations <u>1.2.14</u> and
 1.2.15 (key priority for implementation).

Definitions of terms used in this quality statement

Term or near-term

A gestational age of 35 weeks or more.

Transcutaneous bilirubinometer

A device that uses reflected light to measure the yellow colour (bilirubin level) in the skin. Serum bilirubin measurement (rather than a bilirubinometer) should always be used to determine the bilirubin level in babies:

- less than 35 weeks gestational age
- with jaundice in the first 24 hours of life
- at or above the relevant treatment thresholds for their postnatal age, and for all subsequent measurements
- if the bilirubinometer indicates a bilirubin level greater than 250 micromol/litre

[Neonatal jaundice (NICE clinical guideline 98) recommendation 1.2.15]

Question for consultation

Is the use of transcutaneous bilirubinometers already routine practice?

Quality statement 3: Management of hyperbilirubinaemia:

treatment thresholds

Quality statement

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.

Rationale

Once jaundice is recognised, it is important to know when and how to treat it.

Phototherapy is an effective treatment for significant hyperbilirubinaemia and can

reduce the need for exchange transfusion (procedure involving a complete

changeover of blood) which is necessary only in the most severe cases. The

consistent use of treatment thresholds, alongside NICE guidance, will help to ensure

a balance between the thresholds being low enough to prevent complications (such

as kernicterus) but not so low that phototherapy is used unnecessarily.

Quality measures

Structure

Evidence of local arrangements to ensure the use of standardised treatment

threshold tables or charts that take into account serum bilirubin level, gestational age

and postnatal age.

Data source: Local data collection.

Process

Proportion of babies with hyperbilirubinaemia who are started on treatment in

accordance with standardised threshold tables or charts that take into account serum

bilirubin level, gestational age and postnatal age.

Numerator – the number of babies in the denominator who are started on treatment

in accordance with standardised threshold tables or charts that take into account

serum bilirubin level, gestational age and postnatal age.

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Denominator – the number of babies with hyperbilirubinaemia.

Data source: Local data collection. Contained within NICE CG98 audit support

criterion 13.

Outcome

Incidence of kernicterus.

Data source: Local data collection.

What the quality statement means for service providers, healthcare

professionals and commissioners

Service providers ensure that healthcare professionals have access to and are competent to use standardised threshold tables or charts that take into account serum bilirubin level, gestational age and postnatal age when deciding whether to

start (or not start) treatment for babies with hyperbilirubinaemia.

Healthcare professionals ensure that they use standardised threshold tables or charts that take into account serum bilirubin level, gestational age and postnatal age when deciding whether to start (or not start) treatment for babies with

hyperbilirubinaemia.

Commissioners ensure that they commission services from providers whose healthcare professionals have access to and are competent to use standardised threshold tables or charts that take into account serum bilirubin level, gestational age and postnatal age when deciding whether to start (or not start) treatment for babies

with hyperbilirubinaemia.

What the quality statement means for patients and carers

Babies with high levels of bilirubin are started on treatment for jaundice according to tables or charts that tell the healthcare team the best time to do this. Decisions about starting treatment are based on the baby's blood bilirubin levels, how old they are and how many weeks of pregnancy they were born after.

Source guidance

 Neonatal jaundice (NICE clinical guideline 98), recommendations <u>1.3.4</u> (key priority for implementation) and <u>1.2.13</u>.

Definitions of terms used in this quality statement

Standardised threshold tables or charts

These are tables or charts that help healthcare professionals implement treatment thresholds for phototherapy and exchange transfusion in accordance with NICE clinical guideline 98. These include <u>treatment threshold graphs</u> published on the NICE website. All tables or charts should take into account serum bilirubin level, gestational age and postnatal age.

Quality statement 4: Parent-baby interaction during phototherapy

Quality statement

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.

Rationale

Parents or carers of babies receiving phototherapy may feel anxious about not being able to interact with their baby. Brief interruptions of phototherapy for babies with low bilirubin levels do not adversely affect the baby's treatment. During these breaks healthcare professionals can support parents and carers and encourage them to interact with their baby, including feeding, cuddling and nappy changing. This may help to reduce anxiety for both parents and babies, and improve bonding and parental satisfaction. It may also contribute to the continuation of breastfeeding, where this is the mother's preference. However, breaks in phototherapy are not recommended for babies with moderate or high levels of serum bilirubin (for example, during multiple phototherapy).

Quality measures

Structure

Evidence of local arrangements to ensure that 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.

Data source: Local data collection.

Process

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

DRAFT

Numerator – the number of babies in the denominator whose parents or carers have

the opportunity to feed and cuddle them, and change the baby's nappy, during short

breaks in treatment.

Denominator – the number of babies receiving single conventional phototherapy.

Data source: Local data collection.

Outcome

Feedback from parents or carers on feeling supported to interact with the baby

during single conventional phototherapy.

Data source: Local data collection.

What the quality statement means for service providers, healthcare

professionals and commissioners

Service providers ensure that systems are in place to provide short breaks during

single conventional phototherapy (when clinically safe to do so) to give parents or

carers the opportunity to feed and cuddle the baby, and change the baby's nappy.

Healthcare professionals ensure that they assess whether short breaks during

single conventional phototherapy are clinically safe, and if so, encourage parents or

carers to feed and cuddle the baby, and change the baby's nappy.

Commissioners ensure that they commission services in which short breaks during

single conventional phototherapy are provided (when clinically safe to do so) to give

parents or carers the opportunity to feed and cuddle the baby, and change the

baby's nappy.

What the quality statement means for patients and carers

Parents or carers of babies having a type of treatment called single conventional

phototherapy (in which the baby is placed under a special light) have the opportunity

to feed and cuddle the baby, and change the baby's nappy, during short breaks in

treatment.

Source guidance

• Neonatal jaundice (NICE clinical guideline 98), recommendation <u>1.4.18</u>.

Definitions of terms used in this quality statement

Single conventional phototherapy

Phototherapy given using a single light source that is positioned above the baby. It does not include fibreoptic phototherapy, which allows for parent or carer interaction with the baby without the need for structured breaks in treatment.

Short breaks in treatment

These may last up to 30 minutes, based on clinical judgement. [Neonatal jaundice (NICE clinical guideline 98), recommendation 1.4.18.]

Status of this quality standard

This is the draft quality standard released for consultation from 3 October to 31 October 2013. It is not NICE's final quality standard on neonatal jaundice. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 31 October 2013. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the NICE website from March 2013.

Using the quality standard

Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its <u>Indicators for Quality Improvement Programme</u>. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's What makes up a NICE quality standard? for further information, including advice on using quality measures.

Levels of achievement

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of

100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered by commissioners, providers, healthcare professionals and social care and public health practitioners, patients, service users and carers alongside the documents listed in 'Development sources'

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments are available.

Good communication between healthcare professionals and parents or carers of babies with neonatal jaundice is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Parents or carers of babies with neonatal jaundice in any setting should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

Development sources

Further explanation of the methodology used can be found in the quality standards <u>Process guide</u> on the NICE website.

Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

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

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- Department of Health (2009) Toolkit for high quality neonatal services.
- Department of Health (2008) Neonatal taskforce bulletin.

Definitions and data sources for the quality measures

Neonatal jaundice: audit support. NICE clinical guideline 98 (2010).

Related NICE quality standards

Published

- Postnatal care. NICE quality standard 37 (2013).
- Specialist neonatal care. NICE quality standard 4 (2010).

Future quality standards

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Antibiotics for neonatal infection.
- Blood transfusion in neonatology.
- Premature birth.

Quality Standards Advisory Committee and NICE project team

Quality Standards Advisory Committee

This quality standard has been developed by Quality Standards Advisory Committee 4.

Membership of this committee is as follows:

Professor Damien Longson (Chair)

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Ms Alison Allam

Lay member

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Consultant Old Age Psychiatrist, Manchester Mental Health and Social Care Trust

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The following specialist members joined the committee to develop this quality standard:

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About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the <u>quality standards process guide</u>.

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