Prolonged jaundice

Around a third of infants who breast feed will still be jaundiced at 2 weeks (1). This is normal but certain conditions (eg biliary atresia, G6PD deficiency) must be excluded.

Audit, literature review and review of practice in other networks justify guidance that the majority of babies do not require extensive investigation (2-5). Prolonged jaundice with normal investigations is **no reason** to stop breast feeding.

The purpose of this guideline is to clarify expected timelines for review, and to define the expected points of history, examination and investigation when an infant is referred with prolonged jaundice.

This guideline has been approved by the Neonatal Senior Consultant Team RIE, the Paediatric Senior Consultant team St John's Hospital, Paediatric Gastroenterology and A&E at RHSC, and Community GP and Health Visitor teams.

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Definition

- Visible jaundice persisting *after* 14 days in term infants or *after* 21 days in preterm infants

Practice point:

- A transcutaneous bilimeter (eg “Minolta”) should **not** be used to check bilirubin levels at this age.

Referral Pathway

Key roles and responsibilities

- Midwives will identify any baby who remains jaundiced at the time of the usual transfer of care to the Health Visitor. It has been agreed that where possible, these babies will continue under the caseload of the Community Midwife and will be reviewed by this team at 15 days.
- Thereafter handover of patient information and arrangements for ongoing review will be communicated to the Health Visitor or GP by the Community Midwifery team.
- Before referral to hospital teams, the Community professional will ensure that information detailed in the Prolonged Jaundice pathway (Appendix 1) can be provided.
- All hospital teams will be responsible for ensuring high quality communication occurs with community teams following assessment of the baby, with clear plans for follow up where appropriate.

Referral process

Babies who are jaundiced at or beyond 14 days (term) or 21 days (preterm):

Advise same day attendance at RHSC A&E or SJH A&E any baby who is/has:

- unwell, rash/bruising, feeding poorly, low tone, other neurological signs or lethargic

Advise next working day attendance to RHSC A&E (attend by 10am) or refer by phone to the paediatric registrar at SJH, any baby who:

- has pale (or 'suspect') stools at any time –THIS IS THE MOST IMPORTANT SIGN TO OBSERVE and EMPHASISE ONGOING DAILY ASSESSMENT BY PARENTS
- has a family history of recurrent jaundice or blood disorder or whose parents are consanguineous
- has been formula feeding exclusively without any breastmilk received in the last 7 days
- has not regained birth weight by 14 days and where there is evidence that weight gain is not reassuring; or, where weight gain has become poor since regaining birthweight
- has had previous NNU admission for intensive phototherapy due to suspected haemolysis

All other babies:

- no need to refer to hospital at this stage
- give parents worsening advice and the new prolonged jaundice information leaflet
- ensure parents know to assess stool colour daily using the PiL stool chart (if in colour) or online link (see below)
- review babies weekly until no longer jaundiced and refer as pathway above
- NB: all babies who remain jaundiced at 28 days (term or preterm) should be referred to RIE **neonatal registrar (Page 1610)** or or SJH paediatric registrar (Page 3564) for next Thursday clinic (RIE) or next weekday attendance (SJH)

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Online stool chart
Children's Liver Disease Foundation

History

The following minimum dataset should be covered in every baby

- Do parents feel the baby is well and behaving normally?
- Is the baby breast or bottle fed only? When did the baby last receive any breast milk?
- Was the dried blood spot screening missed?
- Is the baby gaining weight adequately and had exceeded birthweight by 14 days?
- Has the baby had pale stools? (See Appendix 3 for stool colour chart)
- Has the baby had dark urine?
- Is there any family history of note?
- Was the baby jaundiced on the first day of life?
- Did the baby receive phototherapy in the neonatal period? What was the cause of jaundice?
- Is the baby awaiting follow up for a neonatal murmur?
- Was there hypoglycaemia requiring active management before discharge from the neonatal unit?

Other history should be elicited by clinical need.

Examination

- Weight (+birth weight)
- Signs of wellness
- Jaundice
- Pallor
- Hydration status
- Dysmorphic features including coarse features
- Umbilical hernia
- Hepatosplenomegaly
- Hypotonia or other signs of encephalopathy
- Petechia/purpura/bruising
- Look in the nappy – colour of stool (Appendix 3) and urine
- Examine for features suggestive of congenital heart disease

Investigations

Routine: Bilirubin, direct bilirubin only unless concerns about haemolysis of anaemia

Selected: Hb (gas or formal FBC), G6PD (EDTA 1ml, see high risk groups Appendix 3), Group and DAT, thyroid function tests, clean catch urine

Managing abnormal results

- If there is conjugated or mixed hyperbilirubinaemia, extensive investigation is usually required. These cases must be discussed with the on service gastroenterology consultant at RHSC or if outwith normal working hours the general paediatric consultant (both available via switchboard).
    - Refer to the conjugated hyperbilirubinaemia guideline or BSPGHAN guidance.

- Well infants whose results are outside the normal range (eg unconjugated bilirubin, haemoglobin) can still be discharged **with consultant agreement**. Many of these infants do not require further blood tests.

Discharge from clinic and communication

- Well infants who have normal results do not require a follow up appointment for repeat tests
- Parents should be telephoned with the results within 24 hours of being seen
- Template to embed in the discharge letter is available on TRAK: \nnupjclin
    - All sections of the template letter must be completed
    - The letter is a basic minimum standard –relevant clinical information should be added if not included in the template
- Breast milk jaundice may take up to 12 weeks to resolve – it is *not* a reason to stop breast feeding (6)
- Parents should be advised of the following:
    - Breast milk jaundice will steadily improve, but may be present up to 3 months of age (6)
    - No further investigation is required unless the baby:
        - Becomes unwell
        - Develops pale stools/dark urine
        - Looks more jaundiced
        - Is not gaining weight as expected
    - If any of those features develop, parents should contact their own GP for advice
    - Support this information with the Prolonged Jaundice PiL (Appendix 4)

Oversight

- It is the responsibility of the individual who has ordered the investigation to ensure results are chased and acted upon.
- All infants seen as outpatients for prolonged jaundice:
    - in the SCRH and SJH **must** be discussed with a consultant within 24 hours of attendance, and this discussion documented in the discharge letter.
    - in A+E at RHSC or SJH should be discussed with consultant/senior staff as appropriate

References

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2. Hannam S, McDonnell M, Rennie JM. Investigation of prolonged neonatal jaundice. Acta Paediatr. 2000 Jun;89(6):694–7.
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7. Jaundice in the newborn baby [Internet]. CLDF; 2013 [cited 2014 Jul 3]. Available from: http://www.yellowalert.org/file_download.aspx?id=7356

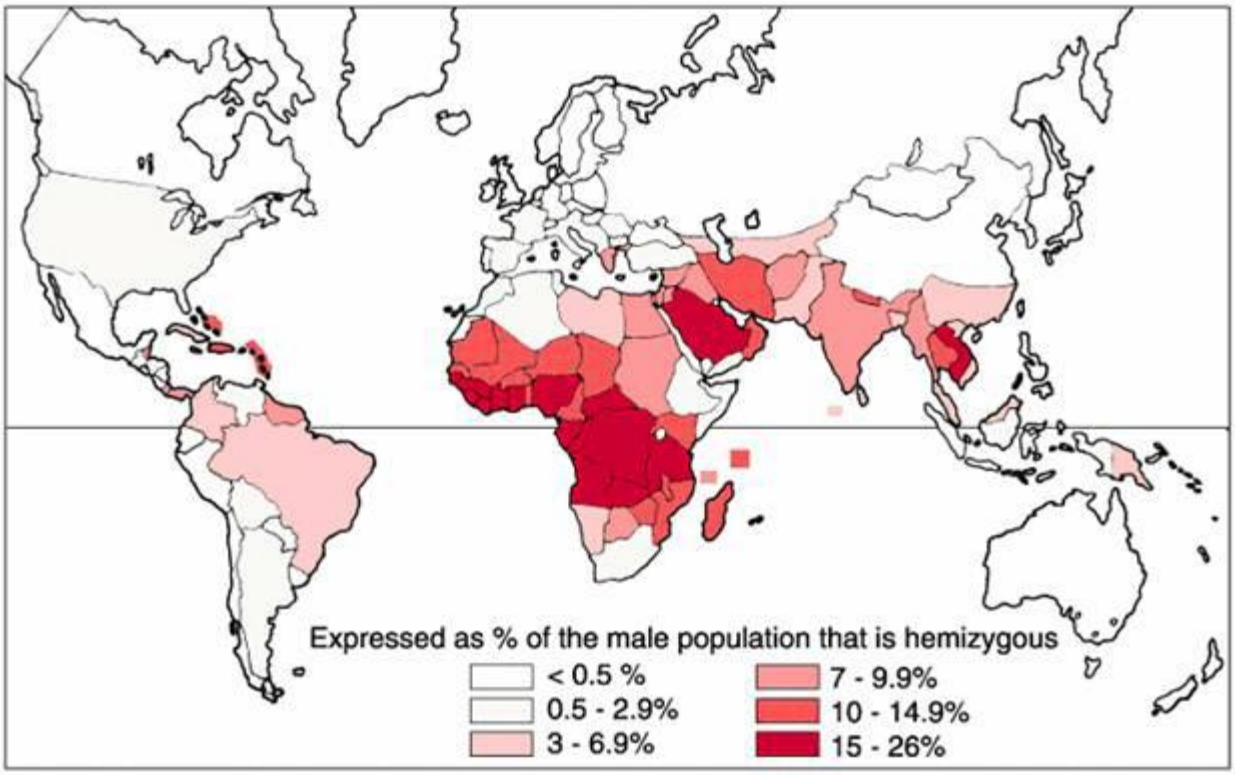
Appendix 1. Important pathology which may result in prolonged jaundice

Hepatic	Obstructive (Appendix 2): Extra-hepatic biliary atresia Choledochal cyst Alagille's syndrome Cystic fibrosis/inspissated bile Ductal fibrosis or cholangitis
	Hepatocellular: TPN associated Neonatal haemochromatosis
Infective	Viral: TORCH, hepatitis B Bacterial: systemic, urinary tract infection
Genetic/metabolic	A1 antitrypsin deficiency Hypothyroidism Galactosaemia, tyrosinaemia Aneuploidy Zellweger's syndrome Panhypopituitarism
Haematological	G6PD deficiency (Appendix 3)
	Blood group incompatibility
	Spherocytosis
	Gilberts syndrome

Appendix 2. Stool Colour Chart

The stool chart below is reproduced from the Children's Liver Disease Foundation parent information leaflet (7) and provides a useful reference. Please note that the colours will vary if printed, and will be dependent on your monitor settings.

Appendix 3. Map showing areas of the world with high incidence of G6PD deficiency.



Appendix 4. Prolonged Jaundice Parent Information Leaflet

What is prolonged jaundice?

Jaundice is described as a yellowing of the skin, and sometimes of the whites of the eyes. It occurs in 90% of newborn infants. Prolonged jaundice is the term for jaundice which is still present after 2 weeks in term babies and after 3 weeks in preterm babies (that is, less than 37 weeks gestation).

What causes prolonged jaundice?

Jaundice is caused by the build up of a dark yellow substance called bilirubin. This is a natural waste product of the normal breakdown of red blood cells. Before birth, the mother's liver removes this product, but after birth the baby's liver must get rid of it on its own.

However, the liver is still immature in newborns, so it is less efficient at clearing waste products. These can build up in the skin and appear as jaundice.

Jaundice usually appears after 2-3 days and gradually disappears on its own by 14 days. However jaundice can often last longer, especially in the breastfed or preterm baby.

Does prolonged jaundice matter?

Prolonged jaundice is usually related to breast milk feeding and is harmless. In this case, jaundice will disappear in the coming weeks and you should continue breastfeeding your baby.

Very rarely prolonged jaundice can be a sign of a liver, thyroid, metabolic or blood problem. This is very uncommon but must be investigated so that treatment may be given if required.

What to expect if your baby remains jaundiced

Term babies who remain jaundiced after 14 days and preterm babies who remain jaundiced after 21 days will be assessed by your Midwife or Health Visitor.

- If there are any concerns your baby will be referred to hospital for further tests
- If there are no other concerns about your baby's health, your baby will be seen again by your Midwife or Health Visitor weekly. If your baby is still jaundiced at 4 weeks of age your baby will be referred to hospital for further tests
- Look at the colour of your baby's nappies every day (see below), and check for other 'red flags'. If any are present please contact your Midwife or Health Visitor urgently for review.
- At clinic, your baby will be examined and a blood test will be performed to check the level of bilirubin in the blood.

When to seek help ('red flags')

Please contact your Midwife or Health Visitor at any time if your baby develops any of the following signs:

- Pale 'suspect' stools (see chart below or online scanning the QR code here)

  This is a very important sign and you should check the colour of your baby's dirty nappies every day

- Dark urine
- Poor feeding
- Sleepiness or excessive crying
- Swollen tummy
- Rash or bruising

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Does prolonged jaundice require treatment?

Babies with jaundice due to breast milk or prematurity will not require treatment, and jaundice will disappear over coming weeks. You should not stop breast feeding.

If tests show that your baby has another reason for jaundice then the treatment depends on the cause.

Further information

If you wish to discuss anything about your baby, please speak to your GP or Health Visitor.

You may wish to download the 'Yellow Alert' app or find more resources at the Children's Liver Disease Foundation by scanning this QR code:

Parent Information Leaflet

Attending the RIE as an Outpatient

An appointment has been made for your baby to attend the Children's Ward as an Outpatient.

Date..... Time.....

Why was this appointment made?

- Most babies attend the Neonatal Service as outpatients after being referred by the Community Midwife or Health Visitor for concerns such as jaundice, feeding difficulties or weight loss. Alternatively, our neonatal team will arrange for some babies to attend the department for reviews or blood tests after being discharged from hospital. It is important to know that depending on the outcome of your visit, your baby might need to be admitted to hospital and you should plan accordingly.

Where do you need to come?

- To the outpatient department on the ground floor of the Simpson Centre for Reproductive Health in the Royal Infirmary of Edinburgh.

What happens when you arrive?

- Please report to reception and a member of the team will come to review your baby.
- Please be aware that you may have to wait before being seen. This is due to the fact that, the team also has responsibilities within the unit (such as attending births or caring for sick patients). We will do our best to see you within 30 minutes following your arrival, but we may not always be able to do so when the unit is very busy.
- If you have waited more than 30 minutes, please come back to the Main Reception and staff will provide information regarding the estimated waiting time.
- Once your baby is seen by our team, a decision will be made regarding treatment
    - If your baby needs blood tests, you may be asked to wait for 1-2 hours until tests are reported, as the results sometimes determine whether your baby will need to be admitted to hospital or not.
    - In other situations, we will advise you to go home and we will phone you with results within 24-48 hours, with any plan for treatment and follow up.

If you need to change the date or time of your appointment or to enquire about test results, please call the Royal Infirmary of Edinburgh and ask to be put through to the Neonatal Unit.

We hope that you find this information useful. If you have any suggestions about how we can improve your experience with our service please speak to staff.

Appendix 6. Information for parents attending Paediatric Ward, St John's Hospital

Parent Information Leaflet

Attending the Children's Ward, St John's Hospital as an Outpatient

An appointment has been made for your baby to attend the Children's Ward as an Outpatient.

Date..... Time.....

Why was this appointment made?

- Most babies attend the Children's Ward as outpatients after being referred by the Community Midwife or Health Visitor for concerns such as jaundice, feeding difficulties or weight loss. Alternatively, our neonatal team will arrange for some babies to attend the department for reviews or blood tests after being discharged from hospital. It is important to know that depending on the outcome of your visit, your baby might need to be admitted to hospital and you should plan accordingly.

Where do you need to come?

- The Children's Ward is located on the second floor directly above labour ward

What happens when you arrive to the Children's Ward?

- Please ring the bell and go to the main reception. You will be directed towards to the waiting area and our team will be informed of your arrival.
- Please be aware that you may have to wait before being seen. This is due to the fact that the team also has responsibilities within the ward (such as attending A&E or caring for sick patients on the ward.) We will do our best to see you within 30 minutes, but we may not always be able to do so when the ward is very busy.
- If you have waited more than 30 minutes, please come back to the main reception and staff will provide information regarding the estimated waiting time.
- Once your baby is seen, a decision will be made regarding necessary treatment.
    - If your baby needs blood tests, you may be asked to wait for 1-2 hours until tests are reported, as the results sometimes determine whether your baby will need to be admitted to hospital or not.
    - In other situations, we will advise you to go home and we will phone you with results within 24-48 hours, with any plan for treatment and follow up.

We hope that you find this information useful. If you have any suggestions about how we can improve your experience with our service please speak to the staff or you can write into the ward with suggestions.