Prolonged jaundice

Objectives:

1. To detect important disorders presenting as prolonged jaundice that require further investigations
2. To avoid over investigation of well babies
3. To avoid unnecessary hospital visits for well babies and their families

Key definitions:

Prolonged Jaundice: Visible jaundice persisting after 14 days in term babies (born > 37 weeks) or after 21 days in preterm babies (born < 37 weeks gestation)

Introduction and background:

A high proportion of babies attending prolonged jaundice clinic fall into the category of well, thriving, breastfed, with minimal jaundice and improving. However, due to concerns about a small number of cases with pathological causes, investigations are aimed to rule out conditions such as biliary atresia where early detection and surgical intervention significantly improves the outcome. It is also important to note other causes of conjugated hyperbilirubinemia listed in Appendix 1.

The aim of the prolonged jaundice screening is to streamline the investigations by removing ambiguity as much as possible. The overwhelming majority of infants who remain jaundiced at 14 days of age will have benign self- resolving breastmilk jaundice.

Practice varies across the UK for prolonged jaundice management. Further audit, literature review and review of practice in other UK networks justify guidance that most babies do not require extensive investigation which causes parental anxiety and unnecessary hospital visits.

We put this guideline forward for approval by the: RIE Neonatal Consultant team, the SJH Paediatric Consultant Team, RHCYP Paediatric Gastroenterology, RHCYP A&E team, General Practitioners in the community and Health Visiting teams.

IT is written in conjunction in keeping with the guidelines advocated by the 'yellow alert' campaign and BSPGHAN guidance.

Two key changes from previous pathway are:

1. ***Moving key responsibility for the management of prolonged jaundice patients to the NCOT team/ acute team without mandatory consultant discussion in RIE.***
2. ***Identifying a cohort of patients in whom we can safely avoid unnecessary investigation.***

Referral pathway

Midwives will identify any baby who remains jaundiced at the time of 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 the team at D15.

A transcutaneous bilimeter (Minolta) should not be used to check bilirubin levels at this age

Patients who have been discharged from the neonatal unit who are jaundiced will already have NCOT follow up in place. New development of Jaundice after discharge is uncommon, and should be discussed with the appropriate neonatal/paediatric registrar depending on site.

Before referral to the hospital, it is essential to have all the following information:

History

a) was the baby term (>37 weeks) or preterm (<37 weeks)
b) feeding history including whether breast or formula fed
c) did the baby receive IM vitamin K?
d) is the baby gaining adequate weight?
e) what colour is baby's stool? (refer to stool chart – Figure 1)
f) is the baby's urine dark? (baby's urine is normally colourless)
g) is there family history of liver disease /blood disorder?
h) did the baby receive phototherapy?

Examination

- examination, including measurement of weight, should be carried out
- access weight chart on Trak if unsure

Patient	**Appropriate referral**
Jaundiced >14d (Term) or 21d (Preterm) AND: **RED FLAGS** • unwell • rash / bruising • feeding poorly * • not active, low tone • other neurological signs and lethargy	Midwives or Health Visitors should advise same day attendance to A&E. Consider whether emergency ambulance is required.
Jaundiced >14d (Term) or 21d (Preterm) AND: • pale stools *(verified visibly by a health professional)* • Formula feeding exclusively • Faltering growth / Not regained birthweight despite feeding well • History of early jaundice, or family history of blood disorder/ recurrent jaundice or parents consanguineous	Midwives or Health Visitors should advise next working day attendance to A&E at RHCYP, ideally around 10am. SJH babies should be referred to the Paediatric registrar (Bleep 3564) as opposed to being advised to attend A&E.
*We recognise there is a wide range of normal within infant feeding. There are no evidence based parameters to quantify "poor feeding", it is often based on an experienced professionals assessment, and may involve not feeding responsively, being too sleepy to feed etc. If there is uncertainty, please call to discuss with the neonatal team for support/ advice.	

ALL other jaundiced babies should continue under community midwife / health visitor care and be reviewed weekly till jaundice is minimal and improving.

Families should be advised to assess stool colour daily using patient information leaflet/ Yellow Alert stool chart (Appendix 2) or Online stool chart until no longer jaundiced.
If develops pale stool or **RED FLAGS,** then they must attend A&E.

FOR BABIES WHO ARE JAUNDICED >28 DAYS:

Jaundiced >28d AND • **Jaundice is minimal and improving** • **exclusively breastfed baby** • **pigmented stools** • **thriving / gaining weight** • **no history of haemolysis (DAT / Coombs negative)** • **no relevant family history of liver or haemolytic disorder** • **family not from G6PD area** • **clinically well, no parental/midwifery concerns** • **Parents can understand and follow and worsening advice/ safety netting.**	*For babies with minimal and resolving jaundice at D28, and ALL the following criteria, the risk of serious pathology is very low.* *These babies DO NOT need to attend clinic for blood sampling.* *Safety netting/Worsening advice should be given as follows:* Families should be advised to assess stool colour daily using patient information leaflet/ Yellow Alert stool chart (Appendix 2) or Online stool chart until no longer jaundiced. If develops pale stool or **RED FLAGS,** then they must attend A+E. Parents should be advised that breast milk jaundice may persist for up to 3 months, and this is not a reason to stop breast feeding The expectation is that this patient group would not require weekly health visitor reviews.
Jaundiced at > 28d Babies with no red flags and does not fulfil ALL of the above criteria in the green box above	RIE: Call 0131 2421833 (acute phone) to Book into next Wednesday clinic @ Neonatal Paediatric: NNU Community Clinic. SJH: Bleep Paediatric Registrar on 3564 to discuss referral Families should be advised to assess stool colour daily using patient information leaflet/ Yellow Alert stool chart (Appendix 2) or Online stool chart until no longer jaundiced. If develops pale stool or **RED FLAGS,** then they must attend A+E. Parents should be given information leaflet in appendix 5/6

Recognising jaundice in babies from Black, Asian and Ethnic Minority background

The NHS Race and Health Observatory (July 2023) highlighted the difficulty in identifying jaundice in babies of varied races and ethnicity. Apart from skin colour, it is recommended looking for pale chalky stools and/or dark urine that stains the nappy (NICE guideline 2023). The Children's Liver Disease Foundation (CLDF) promote the use of stool chart as a guidance for this (Appendix 2).

Investigations

In the absence of any other concerns, further investigations are limited to

- split bilirubin (total bilirubin and conjugated bilirubin fraction)
- G6PD level – if ethnically indicated (see map of affected population – Figure 1)

For babies who are seen in A&E due to having increased risk of pathology, more extensive investigation may be required, this will be determined by the clinician's assessment.

Interpreting results

If conjugated bilirubin level is > 25 micromoles/litre and / or > 25% of the total bilirubin, then the infant should be investigated promptly for possible underlying liver disease/ other pathology (See appendix 1)

In RIE this should be discussed with Neonatal HDU Consultant. It may also be necessary to involve the on-call Paediatric Gastroenterology Consultant (in hours) or General Paediatric Consultant (out of hours) depending on the level of concern.

In SJH this should be discussed with the Consultant responsible for SCBU.

- First and second stage investigations for conjugated hyperbilirubnaemia can be found on the conjugated jaundice guideleine, or BPGHAN guideline https://old.bspghan.org.uk/sites/default/files/guidelines/2016_guideline_for_the_investigation_of_neonatal_conjugated_jaundice.pdf
- Breast milk jaundice is **unconjugated hyperbilirubinemia**
- Well infants whose results are outside the normal range (e.g. unconjugated bilirubin) may still be discharged with consultant agreement. Many of these infants do not require further blood tests.

Discharge from clinic

- Well infants who have normal results (conjugated bilirubin <25 micromoles/litre) do not require a follow up appointment for repeat tests
- Parents should be informed by phone with the results within 24 hours of attending clinic.
- Parents should be advised that breast milk jaundice may take up 3 months to resolve – it is not a reason to stop breast feeding

Discharge letter

- Template in the discharge letter is available on *TRAK: \pjclin*
- This should be saved under clinical correspondence on Trak so that it is visible to other clinical teams in future.
- All sections of the template must be completed

- The letter is basic minimum standard – any relevant clinical information should be added if not included in the template

Oversight

• It is the responsibility of the medical staff to ensure results are chased and acted upon.

In the Simpsons Unit (RIE):

NCOT team will assess the baby in clinic, including ordering blood results.
Acute team will chase results, contact family and document on Trak.
Neonatal Acute registrar will support the NCOT team whenever required.
All patients causing clinical concern or who have abnormal results should be discussed with the acute registrar +/- HDU consultant.

In SJH:

this is usually managed by the medical team who have seen the baby in OPD

Appendix 1- List of causes of conjugated hyperbilirubinemia

Hepatic	Obstructive 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 Galactosaemic, tyrosinemia Aneuploidy Zellweger's syndrome Panhypopituitarism
Haematological	GCPD deficiency Blood group incompatibility Spherocytosis Gilbert's syndrome

Appendix 2: Stool chart:

Please note that this chart is for guidance only as colours may reproduce differently on different monitors or printers. (Provided by the Yellow Alert campaign)

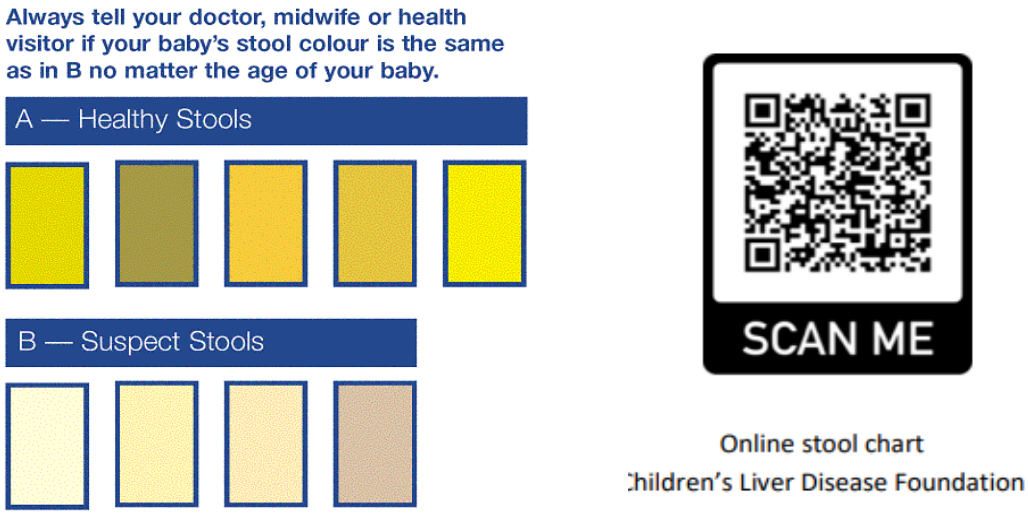
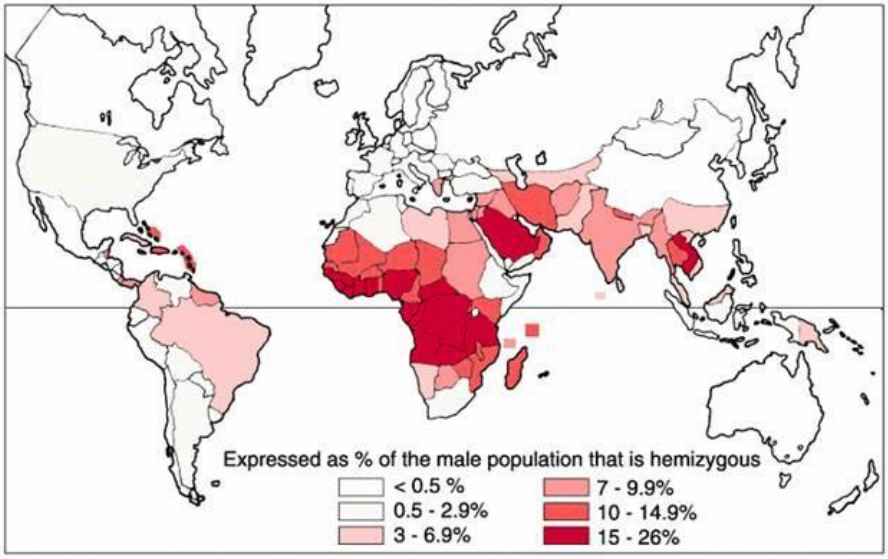


Figure 1 – Distribution of G6PD worldwide



G6PD deficiency is an X-linked genetic disorder, meaning it primarily affects males.
The prevalence of G6PD deficiency is often correlated with regions where malaria has been endemic

<u>Areas with high prevalence:</u>
Sub-Saharan African - including Nigeria, Ivory Coast, Benin)
Mediterranean Region – such as Greece, Italy, Spain
Southeast Asia – including tribal groups in India, the northern Thai border, and Solomon Island
Middle East: Saudi Arabia

Appendix 4: Information for parents and carers
nhsl_prolonged-jaundice_pil_neonates-02-04-26.pdf

Appendix 5: Info for patients attending clinic at RIE

Parent Information Leaflet

An appointment has been made for your baby to attend the Neonatal Unit as an Outpatient.
Date..... Time.....

Why was this appointment made?
Your baby has been referred by the community midwife/Health visitor for investigation of prolonged Jaundice.

Where do you need to come?
To the Neonatal unit on the first 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.
Your baby will be seen and assessed by a member of the team, and a blood test will be performed.
We will advise you to go home, and we will phone you with results within 24 hours, with any plan for treatment and follow up.

What If my baby is unwell or develops pale stools before the appointment?
You should take your baby to A+E straight away.

What if my baby is no longer Jaundiced by the appointment date?
You can call 0131 2422587 and cancel the appointment.

If you need to change the date or time of your appointment or to enquire about test results, please call the number above. Please feel free to leave a voicemail if here is no answer, and someone will get back to you.

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.