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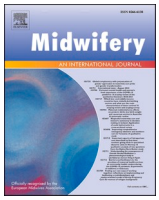

Review Article

# Assessing for neonatal jaundice in the community: an integrative systematic review

Lucy J Hives [a,*], Gill Thomson [a], Cath Harris [b], Deborah King [c], Albert L Kwansa [d], Aasima S Patel [b], Janet Rennie [e], Sarah E Seaton [f], Kylie Watson [c], Ngozi Edi-osagie [c,1], Cheryl Battersby [g,h,1]

[a] Maternal, Parental and Infant Nutrition and Nurture Unit, University of Lancashire, UK
[b] Applied Health Research Hub, University of Lancashire, UK
[c] Manchester University NHS Foundation Trust, Manchester, UK
[d] Research and Innovation, Caribbean and African Health Network (CAHN), UK
[e] EGA Institute of Women's Health, University College London, UK
[f] Department of Population Health Sciences, University of Leicester, UK
[g] Neonatal Medicine, School of Public Health, Faculty of Medicine, Imperial College London, UK
[h] Centre for Paediatrics and Child Health, Imperial College London, London, UK

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ABSTRACT

*Background:* Jaundice is a common condition in newborn babies, usually resolving within two weeks post-birth. A small number of babies develop hyperbilirubinaemia, which if untreated can lead to kernicterus. It is essential to recognise jaundice and assess the bilirubin level as quickly as possible so that timely treatment can be provided. However, currently, there is a lack of knowledge about the feasibility of assessing jaundice reliably in the community.

*Aim:* This integrative review explores the experiences, barriers and facilitators to assessing for neonatal jaundice in community settings in high-income countries.

*Methods:* Five databases (MEDLINE, PsycINFO, CINAHL, Embase and Overton) and backward and forward chaining were undertaken. Findings were analysed and synthesised using a narrative-based approach.

*Discussion:* Searches identified 7076 hits, and after exclusions, nine studies were included. Jaundice assessment methods included visual assessment, Transcutaneous Bilirubinometer (TcB), and Total Serum Bilirubin (TSB). Six themes were developed: 1) Communication, 2) Knowledge and skills, 3) Time and resources, 4) Variation in post-discharge care, 5) Type of community setting and 6) Impact of community screening. TcB was reported to be more accurate than visual inspection, and less time consuming, invasive and costly than TSB.

*Conclusion:* Available insights highlight the need for clear communication and care pathways, and training and education for healthcare professionals and parents. Further research is needed to determine the optimal TcB derived threshold values for hyperbilirubinaemia and accuracy among babies with dark skin tones.

## Introduction

**Statement of significance**

| | |
|---|---|
| Problem or Issue | If hyperbilirubinaemia in newborn babies is not diagnosed and treated quickly it can lead to kernicterus. |
| What is Already Known | Different assessment methods are available for assessing jaundice including visual assessment, transcutaneous bilirubinometry and total serum bilirubin. As bilirubin continues to rise in the first week of life, it is crucial to assess for |

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* Corresponding author at: Maternal, Parental and Infant Nutrition and Nurture Unit, School of Nursing and Midwifery, University of Central Lancashire, Preston PR1 2HE, UK.
*E-mail address:* LHives1@lancashire.ac.uk (L.J. Hives).

[1] Joint Principal Investigators

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(*continued*)

| Statement of significance | |
|---|---|
| | jaundice in babies discharged home. In some high-income countries there are care pathways and guidelines in place, but challenges of implementation persist. |
| What this Paper Adds | In high-income countries, barriers and facilitators to assessing for jaundice and hyperbilirubinaemia in the community include communication issues, education needs for healthcare professionals and parents, and factors that create delays with diagnosis. |

*Neonatal jaundice and its risks*

Jaundice is a very common condition in newborn babies, with around 60 % of term and 80 % of preterm babies developing the condition within the first week of life (Amos et al., 2017). Jaundice causes the skin, sclera, and mucous membranes to turn yellow due to high levels of bilirubin in the blood. Bilirubin is produced during the breakdown of excess red blood cells: it is usually processed by the liver and exits the body in stools. Jaundice that presents in the first 24 h of life is usually pathological and needs an urgent review in secondary care (Amos et al., 2017). Physiological jaundice normally presents after the first 24 h and peaks between days 2 and 5 when most babies have been discharged to community care. Most cases of physiological jaundice will resolve without needing any treatment. While most jaundice seen in community settings is physiological, pathological jaundice can continue to present after the first 24 h and requires prompt assessment and, where indicated, urgent treatment (Sgro et al., 2006).

Healthy babies become jaundiced for several reasons including rapid red cell turnover, slow gut motility and immature liver enzymes (Mitra and Rennie, 2017). In a small number of babies (~5 %) there is a disorder of red cells, metabolic processes or liver disease (Mitra and Rennie, 2017). In these cases, bilirubin from red cell breakdown circulates in the blood bound to albumin; this form of "unconjugated bilirubin" can cross the blood brain barrier and is neurotoxic. Exposure to light of a certain wavelength (phototherapy) can be used to reduce the level of unconjugated bilirubin (Mitra and Rennie, 2017), but if a rapid reduction of a very high level is required, an exchange blood transfusion must be done (NICE, 2010). Intravenous immunoglobulin (IVIG) is another therapy that can sometimes prevent the need for exchange transfusion, especially when bilirubin levels are rising despite other treatments (NICE, 2010). If high levels of bilirubin are not treated, this can lead to kernicterus (a type of irreversible brain damage).

*Challenges and innovations in community-based assessment*

In high-income countries such as Canada, national guidance includes universal assessment for jaundice in newborns using Total Serum Bilirubin (TSB) measurement, and assessment of breastfeeding and jaundice every 24–48 h until feeding is established (Barrington Sankaran, 2007). Similarly, in the United States (USA), the American Academy of Pediatrics guideline recommends universal jaundice assessment at 24–48 h of age with a Transcutaneous Bilirubinometer (TcB) or TSB (Kemper et al., 2022). However, despite these guidelines being in situ, there are challenges in implementing assessment methods in some community settings (Barrington Sankaran, 2007; Salem-Schatz et al., 2004).

In the United Kingdom (UK), early postnatal discharge is encouraged when the mother and infant are well. Therefore, community surveillance for bilirubin is important to ensure early detection and treatment as bilirubin levels typically continue to rise within the first week of life. Currently, there is growing concern that changes in skin colour are more difficult to detect in babies with dark skin tones. This is particularly concerning as half of kernicterus cases are from non-caucasian groups (Johnson et al., 2009; Rennie, 2019; Watchko, 2010) and Black and Asian babies are at higher risk of severe hyperbilirubinaemia (Manning et al., 2007; Setia et al., 2002). The UK's National Institute for Health and Care Excellence (NICE) guidance do not recommend a visual method alone for assessing jaundice (NICE, 2014; Rennie et al., 2010). National initiatives such as the ATAIN program (Avoiding Term Admissions into Neonatal Units) and the NHS Race and Health Observatory recommend objective assessments, increasing awareness, and educational resources (Battersby et al., 2017; NHS Race and Health Observatory, 2023) to improve the speed of diagnosis, and particularly amongst infants with dark skin tones who face increased risks.

In the UK, the responsibility of jaundice surveillance in the first 14 days following birth, lies with community midwives. Community midwives are responsible for assessing jaundice and deciding when further investigation (such as a TSB or a review by a medical professional) is necessary. Objective methods of assessing jaundice in the community and thresholds to conduct additional invasive investigations vary due to differences in available resources and established local guidelines. NICE recommend undertaking a blood test when TcB is not available and visual inspection suggests jaundice (NICE, 2014). Although, TcB is not suitable for babies born under 35 weeks gestation, <24 h old, or for those who are already receiving phototherapy (NICE, 2014). However, a blood test is more invasive and time-consuming compared to other approaches such as by a TcB, which is non-invasive and provides results at the point of care. A recent Cochrane review (Okwundu et al., 2023) of TcB versus TSB, found that TcB was a good method for detecting hyperbilirubinaemia in newborns with a high sensitivity of 74–100 % (specificity 18–89 %). The review included 23 high-quality studies with a total of 5058 participants, but there was heterogeneity in the TcB devices, threshold values for hyperbilirubinaemia, and the age and ethnicity of included infants. Some studies have also found that TcB overestimates serum bilirubin in babies with dark skin tones leading to unnecessary treatment (Thomson et al., 2008; Wainer et al., 2009), whereas other studies found that TcB underestimates bilirubin by 25 ± 35 micromol/L (Szabo et al., 2004).

Recently, there have been new and developing methods of diagnosing jaundice. Two notable innovations are the AJO—Neo (Hadler et al., 2020) and SAMIRA (Banerjee et al., 2023) devices, both offering non-invasive non-contact bilirubin measurement using probes emitting light through the thumbnail to the blood vessels. AJO—Neo uses reflected light to estimate bilirubin levels, while SAMIRA uses spectroscopy and AI to measure haemoglobin, bilirubin, and oxygen saturation. In studies involving 1968 and 4318 neonates respectively, both devices showed strong correlation with TSB values and high clinical accuracy across a range of neonatal conditions (Banerjee et al., 2023; Hadler et al., 2020). Smartphone applications have also been developed (Hegde et al., 2023). For example, the Picterus® Jaundice Pro smartphone app and calibration card (Picterus®, 2025) which can be used by both parents and healthcare professionals to estimate bilirubin levels from images of an infant's chest. Further there is an ongoing study led by University College London Hospitals exploring the use of the neoSCB smartphone app to diagnose jaundice by inspecting the sclera (Leung et al., 2024).

*Gaps and inequities in practice*

Working in a community setting can be particularly challenging due to parents' misconceptions of causes and risks (Kaplan et al., 2019) and the time needed to undertake the tests (Trasancos and Horey, 2024). Research also highlights issues around a lack of training for healthcare professionals on neonatal jaundice generally and the clinical guidelines available for use, varied opinions about the methods used to assess jaundice, and concerns regarding the costs and benefits of early detection in the community (Thomas et al., 2022; Trasancos and Horey, 2024).

Community assessment can lead to early detection of jaundice, prevention of unnecessary hospital admissions, reduction in unnecessary treatment and avoidance of long-term health implications (NHS Race

and Health Observatory, 2023). However, there is a lack of comprehensive insights about implementation related issues for community-based jaundice assessment. We aimed to address this evidence gap by undertaking an integrative systematic review of existing literature to explore the barriers and facilitators associated with assessing for jaundice and hyperbilirubinaemia in newborn infants in community settings. This evidence is critical to inform suitable interventions or support to facilitate its uptake and ensure timely access to appropriate care. Addressing these insights will help inform suitable interventions or support strategies to enhance the acceptability and reliability of assessing jaundice in the community, improve access to timely care, and ultimately reduce morbidity and kernicterus. This integrative systematic review is part of a wider program of research which aims to understand current practice in the assessment of neonatal jaundice in UK community settings.

## Aim and review question

To identify and synthesise the findings from primary research and hospital-based evaluations undertaken in high-income countries about the experiences, barriers, and facilitators to diagnosing neonatal jaundice in babies aged 0–14 days in community settings. The review question was: 'what are the experiences, barriers and facilitators to diagnosing neonatal jaundice in community settings?'.

## Methods

An integrative systematic review, using the methodology of Whittemore & Knafl (Whittemore and Knafl, 2005), was conducted following PRISMA and Cochrane best practice guidelines. This approach was chosen to synthesise evidence from diverse methodologies, enabling a broad understanding of neonatal jaundice assessment in high-income, community settings and generating insights that are both evidence-based and practically relevant. The review was registered on PROSPERO (ID: CRD42024559622).

### *Eligibility criteria*

Research studies (or hospital-based evaluations) exploring the experiences, facilitators and barriers to healthcare professionals assessing for jaundice in infants aged 0–14 days in community settings were included. Studies of assessment of jaundice in hospital settings, as well as studies of accuracy only were excluded. Any peer-reviewed, empirical studies or hospital-based evaluations employing qualitative, quantitative, or mixed methods designs were included. Grey literature (e.g., conference abstracts, theses) were excluded. Research from any high income countries (Metreau et al., 2024) were included due to their similarity with the UK healthcare system. There were no limits on the methods of assessment (e.g., total serum bilirubin, non-invasive transcutaneous bilirubinometer, visual assessment, smartphone apps, etc.), language or year of publication.

### *Search strategy*

The following databases were searched on 18th June 2024: MEDLINE (Ovid), PsycINFO (EBSCOhost), CINAHL (EBSCOhost), Embase (Ovid) and the Overton (https://www.overton.io/) grey literature database (for empirical-based evaluations of community screening). The search strategy was developed by an information specialist in collaboration with the review team and was adapted for use in each database. The search strategy included relevant subject headings and keywords relating to the concepts of jaundice, newborn babies, and barriers and facilitators. The search terms for newborn babies were taken from the Cochrane Review by Okwundu et al. (Okwundu et al., 2023). No date, language or other limits were applied to the searches. The full search strategy for each database can be found in **Supplementary File 1**. Reference list checking of included studies, as well as forward citation searching using Google Scholar, were conducted to identify additional articles.

### *Study selection*

All identified references were imported into EndNote (version X9, Clarivate Analytics, Philadelphia, PA), de-duplicated, and then uploaded to Rayyan® (an online collaboration platform designed to support systematic reviews). Title and abstract screening and full-text screening were conducted by three reviewers, with each article being screened blind by two reviewers. Papers written in languages other than English were to be translated using Google Translate so they could be assessed for inclusion. Discrepancies were resolved through discussion at each stage, and if needed with a third reviewer.

### *Data extraction*

A pre-defined Microsoft Excel data extraction form was created to record: first author, year of publication, study title, journal, country, research aim, research design, research methods, data collection methods, measurement scales, type of community setting, number of participants, sampling/recruitment methods, type(s) of assessment used, key findings. Data extraction was completed by three researchers, with data extracted from each study by two researchers.

### *Assessment of methodological quality*

The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used to assess the quality of each included paper. Quality appraisal was undertaken by two reviewers with discrepancies resolved by discussion and with a third reviewer where necessary.

In contrast to the protocol for this systematic review (which stated that two independent reviewers would be involved in at least 20 % of the study selection, data extraction and quality appraisal), two independent reviewers were able to be involved in selecting, extracting and appraising all studies. Inter-rater reliability was therefore not calculated.

### *Data synthesis*

Findings from the included studies were imported into NVivo (version 14) qualitative analysis software.

Due to the heterogeneity in papers, a quantitative analysis such as meta-analysis was not appropriate, and so a narrative-based analysis approach was adopted (Whittemore and Knafl, 2005). This approach was adopted to enable deeper insight into how healthcare professionals, parents, and caregivers experience and interpret neonatal jaundice assessment in community settings. The findings from a selection of papers were read to develop an initial coding framework, with the framework then developed and refined as coding progressed. Once all the findings had been coded, the codes were synthesised into sub-themes and themes to represent the whole data set. Data analysis was led by the first author, with ongoing discussions with a second reviewer. All the review team contributed to the final reporting.

## Results

### *Study selection*

Database searches identified 7076 papers, 2453 duplicates were removed. 4548 and 66 papers were excluded during title/abstract and full-text screening, respectively. A further 48 studies were identified through reference and citation checking, with 47 excluded. In total, nine studies met the inclusion criteria and were included. The study selection process is detailed in the PRISMA flow diagram (Fig. 1).

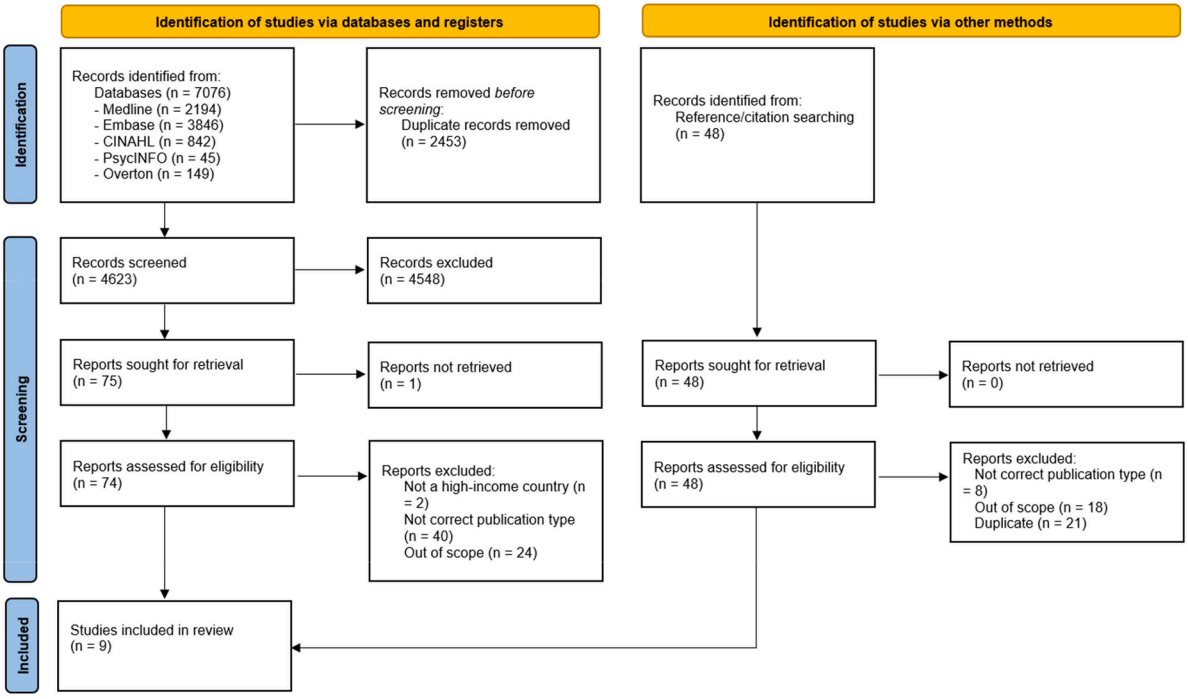


**Fig. 1.** PRISMA flow diagram.

*Study characteristics*

Characteristics of the included studies are detailed in Table 1. Studies were published from 2004–2024 (two-thirds from 2018 onwards) and were conducted in Canada ($n = 3$), Australia ($n = 2$), the Netherlands ($n = 2$), USA ($n = 1$) and Israel ($n = 1$). All included studies were written in English; no papers written in other langauges were eligible for inclusion. Articles were cross-sectional studies ($n = 5$), cohort studies ($n = 2$), and qualitative studies ($n = 2$). A range of data collection methods were used including health and audit datasets ($n = 4$), surveys ($n = 2$), interviews ($n = 2$) and focus groups ($n = 1$).

Community settings studied included home ($n = 6$), community clinics ($n = 1$) and healthcare professionals working in the community generally ($n = 3$). Assessment tests included TSB ($n = 5$), visual assessment ($n = 4$), TcB ($n = 2$), estimation of TSB ($n = 1$), an unspecified bilirubin test ($n = 1$) and general assessment unspecified ($n = 1$). Participants included newborns ($n = 4$), mothers ($n = 2$), doctors ($n = 3$), midwives ($n = 2$), paediatricians ($n = 1$), maternity care assistants ($n = 1$) and policy professionals ($n = 1$).

Only one study detailed participant ethnicity (Khajehei et al., 2022), one provided percentages of Jewish and Arab participants (Kaplan et al., 2019) and one stated the percentage of Caucasian participants (van der Geest et al., 2022).

*Methodological quality*

Included studies scored between 40–100 % on the MMAT (Hong et al., 2018) (see Table 1). Reasons for these variations include a lack of clarity on fidelity of the data and its completeness (McClean et al., 2018; Wainer et al., 2012), unrepresentative samples (Kaplan et al., 2019; Mateo et al., 2013), inappropriate data collection and statistical methods (Khajehei et al., 2022), unclear methods (Mateo et al., 2013), high risk of nonresponse bias (Mateo et al., 2013) or risk of bias being unclear (van der Geest et al., 2022) (see **Supplementary File 2).**

Overall, six themes were developed: 1) Communication, 2) Knowledge and skills, 3) Time and resources, 4) Variation in post-discharge care, 5) Type of community setting and 6) Impact of community screening, discussed in more detail below.

*Communication*

Communication between clinicians was discussed in two papers. In one paper from the USA, community physicians and nurses reported being uninformed of a baby's birth, causing delays in home visits (Salem-Schatz et al., 2004). There was also confusion around who was responsible for the newborn in their first weeks of life: hospital or community health professionals. This led to confusion for parents about who they should contact and for community nurses, where to send bilirubin test results. Further, community clinicians did not always have access to the baby's data (e.g., gestational age, exact time of birth, or laboratory results) which were needed to make evaluation and treatment decisions. Another study found issues with maternity care assistants (MCAs) not reporting visual jaundice to the community midwife which meant the community midwives were unaware of the urgent need for TSB testing (van der Geest et al., 2022).

Communication between healthcare professionals and parents was discussed in three papers. In two studies, MCAs, nurses and physicians expressed reluctance about talking to parents about hyperbilirubinaemia antenatally in case this exacerbated parental concerns (Salem-Schatz et al., 2004; van der Geest et al., 2022). Another study found that parents received inconsistent information regarding the need for follow-up within 72 h post-discharge for jaundice evaluation (Kaplan et al., 2019). Home care nurses in one study described challenges when mother's contact information was not updated as:

> '*a lot of times, they'll go and stay at their mom's house. And when home care goes to see them, they'll either be at the other residence, or no one's answering the phone*' (Salem-Schatz et al., 2004; pp.596).

Parents also wanted more opportunities for post-discharge communication with clinicians (Salem-Schatz et al., 2004) and clearer information about how this could be facilitated (van der Geest et al., 2022).

*Knowledge and skills*

One survey study from the Netherlands (van der Geest et al., 2021) explored MCA's ($n = 1366$) knowledge of hyperbilirubinaemia including the pathophysiology, recognition and treatment of

**Table 1**
Characteristics of included studies (grouped by country).

| Study | Country | Study aim | Research design | Data collection methods | Community setting | Participants | Type of jaundice assessment | Key findings | Quality appraisal rating |
|---|---|---|---|---|---|---|---|---|---|
| Khajehei (2022) | Australia | To evaluate a large midwifery-led, paediatrician-overseen home jaundice surveillance and home phototherapy programme. | Retrospective cohort | Prospectively completed maternity database and individual electronic medical records | Home | 4308 infants | TSB | Of the 4308 babies eligible for the study (birth gestation ≥35 weeks, discharged at 4–96 h and receiving care from midwifery-at-home), jaundice requiring phototherapy was diagnosed for the first time at home in 323 (7.5 %) infants. Of these, 243 (75 %) were suitable for home phototherapy and 80 (25 %) were readmitted to hospital. | 60 % |
| Trasancos (2024) | Australia | To explore health professionals' experiences and perspectives of neonatal jaundice management in Australia to identify possible gaps in the delivery of evidence-based care. | Qualitative descriptive | Semi-structured interviews | The nurses interviewed worked within the hospital and in the community | 41 HCPs (doctors, nurses, midwives, clinical education group, policy professionals) | Assessment in the community generally. TSB. | Early discharge led to variability in post-discharge care, where neonatal jaundice management was variously described as 'haphazard' or dependent on 'competing demands' with 'no dedicated surveillance' measures in place. While one neonatologist described a robust community system, numerous others, including other neonatologists, did not concur:<br>"Need better way of streamlining taking serum bilirubin levels at home. Would need to report to the registrar. All midwives at home should perhaps carry a bilirubinometer. Institutions vary—each hospital will have its own policies. [….] Need resources for daily home visits for a minimum of 3 days until the maternal and child health nurse kicks in; need lactation support." | 100 % |
| Wainer (2012) | Canada | To assess the impact of programmatic and coordinated use of TcB on the incidence of severe neonatal hyperbilirubinemia and measures of laboratory, hospital, and nursing resource utilisation. | Prospective cohort | Health region databases and laboratory services, pre and post-program implementation | Home, community clinic | 28,908 infants (14,112 historical cohort assessed by visual inspection/ 14,796 prospectively enrolled healthy infants offered routine TcB in hospital and community settings) | Visual inspection vs TcB | After the implementation of a TcB community program there was a 54.9 % reduction in the incidence of severe initial TSB values and a 22.9 % reduction in frequency of TSB measurements in the community. There was no significant change in the initial nursery length of stay. The overall phototherapy rate significantly decreased from 6.09 % to 4.97 %, there was a reduction of 15.4 h in the average age at readmission for phototherapy and there was a reduced duration of readmission for phototherapy. Public health nurse encounters tended to be earlier and more often, however there was an increase in infants having no public health nurse encounters. | 60 % |

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**Table 1** (*continued*)

| Study | Country | Study aim | Research design | Data collection methods | Community setting | Participants | Type of jaundice assessment | Key findings | Quality appraisal rating |
|---|---|---|---|---|---|---|---|---|---|
| Mateo (2013) | Canada | To determine current practices among medical practitioners in Ontario in the screening for, and management of, neonatal hyperbilirubinemia. | Cross-sectional | Survey | Hospital and community settings. 45 % of healthcare professionals worked in community practice. | 321 HCPs (family medicine practitioners, general practitioners, midwives, paediatricians) | TSB | The use of AAP or CPS guidelines as a resource to guide jaundice management was reported by 41 % of family physicians, 75 % of paediatricians, and 69 % of midwives. Fewer family physicians (67 %) reported that AAP or CPS guidelines were accessible or easy to use compared with midwives (80 %) and paediatricians (87 %). Routine bilirubin tests were ordered before discharge by 42 % of family physicians, 63 % of pediatricians, and 22 % of midwives. Routine postdischarge follow-up within 72 h was planned by 60 % of family physicians, 89 % of pediatricians, and 100 % of midwives. | 40 % |
| McClean (2018) | Canada | To assess costs associated with total serum bilirubin (TSB) and transcutaneous bilirubinometry (TcB) for jaundice screening in hospital and in urban and rural community settings. | Cross-sectional | Organisational health data sets | Home (urban and rural) | The number of postpartum unit discharges for time period 1 and 2 were 2466 and 2493 infants, respectively. | TSB vs TcB-TSB | There were 3399 and 3331 visits during the community follow-up program in time period 1 and 2, respectively. In time period 1, there were 3844 blood draws for TSB measurement. In time period 2, there were 1099 blood draws for TSB and 6523 TcB screens.<br>TSB in the community was more costly and time consuming than TcB, and even more so in rural settings. This was due to travel time, laboratory expenses and mileage. The estimated cost per TcB screen in community (urban and rural) settings was $3.76, while the estimated cost per TSB screen in urban and rural community settings was $50.21 and $65.03, respectively. The estimated overall 6-month saving with the TcB–TSB community program was $6417. | 60 % |
| Kaplan (2019) | Israel | To assess implementation of the Israel Neonatal Society's 2008 guidelines for universal community assessment of jaundice within 72 h of discharge from birth hospitalisation | Cross-sectional | Structured interviews | Community clinic | 659 mothers | Visual assessment | 217 (32.9 %) mother-infant dyads attended a community clinic within 72 h of discharge from hospital. Attendance was higher among mainstream Jewish participants (40.5 %) and lower among the ultra-orthodox (Haredi) and Arab subsets (20.2 % and 18.2 % respectively). Mothers who did not attend the clinic gave reasons such as feeling that the examination was unnecessary, the belief that the community clinics exist for the purpose of immunisation | 80 % |

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**Table 1** (*continued*)

| Study | Country | Study aim | Research design | Data collection methods | Community setting | Participants | Type of jaundice assessment | Key findings | Quality appraisal rating |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | only, bad weather, maternal illness or not understanding the instruction. Newborn discharge letters relating to the early post-discharge follow-up for hyperbilirubinemia were varied and inconsistent. | |
| Van der Geest (2021) | Netherlands | To assess knowledge and skills of maternity care assistants (MCAs) regarding neonatal hyperbilirubinaemia. | Cross-sectional | Survey | Home | 1465 MCAs | Visual assessment. Estimation of TSB based on visual assessment. | MCAs who had attended in-service training on neonatal hyperbilirubinaemia in the last year had a higher level of knowledge than those who had not attended training. 90 % felt their knowledge on hyperbilirubinaemia was adequate, however 63 % wanted additional training. MCAs identified the following causes of late diagnosis: insufficient visual assessment, late/delayed blood sample collection, late/delayed referral to secondary or tertiary care, late/delayed consultation with a paediatrician. 82 % considered themselves capable of visually assessing neonatal jaundice, however there was substantial variation when asked to assess 3 photographs of babies with jaundice. 12 MCAs noted that the skin colour made visual assessment more difficult. | 100 % |
| van der Geest (2022) | Netherlands | To describe characteristics of neonates with severe neonatal hyperbilirubinaemia (SNH) and to gain more insight in improvable factors that may have contributed to the development of SNH. | Quantitative descriptive | Perinatal audit data | Community generally. Home visits mentioned. | 109 infants | Visual assessment and TSB | There were a range of difficulties in observation and communication by both MCAs and community midwives, e.g., severity of jaundice was underestimated; no follow-up was provided for hyperbilirubinaemia; neonates were not always assessed by the community midwife if an MCA reported hyperbilirubinaemia; or the MCA did not mention the risks of severe neonatal hyperbilirubinaemia. TSB was time consuming, delaying diagnosis and treatment. | 80 % |
| Salem-Schatz (2004) | USA | To explore existing barriers to timely newborn follow-up and strategies to address them. | Cross-sectional qualitative | Focus groups | Home | 41 HCPs (physicians, nurses, mothers) | Bilirubin test (type not specified) | Community-based clinicians were sometimes not notified of a baby's birth. There was confusion around who is responsible for the newborn in the first week of life (hospital or community clinicians). Many home care agencies do not allow nurses to obtain blood for TSB; there is a wait | 80 % |

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**Table 1** (*continued*)

| Study | Country | Study aim | Research design | Data collection methods | Community setting | Participants | Type of jaundice assessment | Key findings | Quality appraisal rating |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | for a physician. There can be delays with nurses getting blood to the laboratory; some asked parents to do so or sent infants back to the hospital to have blood drawn.<br>Physicians expressed concern about a lack of reliability of some home care services. Parents sometimes refused home care services citing out-of-pocket costs and insurance coverage issues.<br>Physicians suggested improvements such as bilirubin screening tests for all babies at 72 h of age and an outpatient visit a day after discharge.<br>Nurses suggested an additional educational visit before delivery.<br>Mothers varied as to their preference for site and type of provider for a follow-up visit and also suggested flexible appointments, drop-in visits, and separate office hours/waiting areas for well babies.<br>Physicians noted that the evaluation of hyperbilirubinemia can be difficult for parents to understand Physicians and nurses were reluctant to discuss hyperbilirubinemia with parents before delivery.<br>Suggestions for clinician education: risk factors for severe hyperbilirubinemia and identifying hyperbilirubinemia in dark-skinned populations. Suggestions for parent education: support groups for new and expectant parents, breastfeeding support, and educational posters in the newborn nursery. | |

**Abbreviations:** AAP: American Academy of Pediatrics; CPS: Canadian Paediatric Society; HCP: Healthcare professional; MCA: Maternity care assistant; SNH: Severe neonatal hyperbilirubinaemia; TcB: Transcutaneous Bilirubin; TSB: Total serum bilirubin.

hyperbilirubinaemia, and also asked them to assess their professional experience with hyperbilirubinaemia. MCAs who had completed recent (within the last 12 months) in-house training on hyperbilirubinaemia ($n = 309$) had higher knowledge scores than those who had not completed recent training ($n = 1002$) (64 % vs 57 %, $p = 0.024$). The majority (90 %) of MCAs felt that their knowledge of hyperbilirubinaemia was adequate, however 63 % requested additional training (van der Geest et al., 2021). Healthcare professionals in the study by Salem-Schatz and colleagues (Salem-Schatz et al., 2004) suggested that clinician education should include risk factors for severe hyperbilirubinaemia, identifying hyperbilirubinaemia in dark-skinned populations, and a guideline card that covers near-term infants (Salem-Schatz et al., 2004).

While most MCAs ($n = 1120$, 82 %) in the van der Geest (van der Geest et al., 2021) study considered themselves capable/very capable of visual assessment, they were overconfident in their abilities, with MCAs (van der Geest et al., 2022, 2021) and community midwives (van der Geest et al., 2022) often underestimating the severity of jaundice. Accuracy of TSB estimation based on visual assessment did not vary for MCAs with differing levels of knowledge ($p = 0.067$), and there was no significant association between MCA's self-rated capability to assess jaundice and their actual ability to correctly estimate TSB ranges based on visual inspection ($p = 0.794$). While MCAs were likely to choose an active action plan for babies who were visually assessed as being more yellow, a large proportion ($n = 860$, 63 %) did not suggest a TSB test being undertaken.

Some MCAs noted that visual assessment was more difficult in 'non-Caucasian neonates' (van der Geest et al., 2021). Furthermore, in the study by Trasancos & Horey (Trasancos and Horey, 2024), while there was recognition of jaundice admissions being higher in Asian populations, only five out of 41 healthcare professionals interviewed (two paediatricians, a neonatologist, midwife and neonatal nursing educator) mentioned considering the changing demographics of their population (Trasancos and Horey, 2024).

Challenges to educating parents were identified. These included shorter hospital stays and parent comprehension (Salem-Schatz et al., 2004; Trasancos and Horey, 2024). Suggestions for parent education included support groups for new and expectant parents, education posters in newborn nurseries, and providing refrigerator cards with "early warning signs" of newborn hyperbilirubinaemia (Salem-Schatz et al., 2004). One nurse also suggested that prenatal home visits may be beneficial for parental memory retention:

> *'When you have a mom who's just delivered—and she is absolutely exhausted, and she is going to go home the next day, and you are trying to do that whole critical teaching in that short span of time. How much does she really retain? That's why I was saying prenatally. If you can get some of the things in, and you talk about newborn care, and actually teach a little bit more and then you can reinforce it.'* (Salem-Schatz et al., 2004)

### *Time and resources*

Four papers discussed reasons for delays with jaundice assessment. In one study (van der Geest et al., 2021), delays were caused by insufficient visual assessment (i.e. late or inaccurate) by a midwife or MCA, delayed blood sample collection, referral to secondary or tertiary care, and needing to wait for a consultation with a paediatrician. The McClean et al. (McClean et al., 2018) paper found that the average time taken for a nurse to take a blood sample for TSB was significantly longer than for performing TcB (12.52 min (10.44–14.59) vs 2.94 min (2.55–3.33), $p < 0.001$. This was supported by a further study (van der Geest et al., 2022) which found the process of TSB testing led to delays of several hours in diagnosis of severe neonatal hyperbilirubinaemia. Delays when blood samples for TSB were taken at home were associated with home care agencies lacking standing orders for nurses to take the samples (a physician was needed) (van der Geest et al., 2022) and transport delays to the laboratory (Salem-Schatz et al., 2004), particularly for rural versus urban communities (McClean et al., 2018; Salem-Schatz et al., 2004). Delays also happened after admission to hospital with jaundice, for example when TSB results remained unnoticed or blood for exchange transfusion was not ordered (van der Geest et al., 2022). The Salem-Schatz et al. (Salem-Schatz et al., 2004) study interviewed physicians and nurses, and concluded that:

> *'Existing systems for collecting, processing, and reporting bilirubin levels do not keep pace with the newborn's rapidly shifting physiology in the first week of life and therefore do not allow for timely decision making'* (Salem-Schatz et al., 2004; pp.596).

Physicians were concerned about the reliability of some home care services, as visits were sometimes not scheduled promptly or not conducted by paediatric nurses (Salem-Schatz et al., 2004). Clinicians reported engaging in several "work-arounds" for these barriers, including having parents take the sample to the lab and wait there until results are available or sending infants back to the newborn nursery or birth hospital's lab to have blood drawn (Salem-Schatz et al., 2004).

One study reported that the costs of jaundice assessment varied by the test used and the assessment location (hospital, urban community setting, rural community setting) (McClean et al., 2018). In this study, the estimated cost of a TcB test itself was $3.54 in hospital and $3.76 in urban and rural community settings. The cost of a TSB test was $15.82 in hospital, and $50.21 and $65.03 in urban and rural community settings respectively. Insurance issues, such as paediatric visits not being covered by insurance policies were mentioned in one study from the USA (Salem-Schatz et al., 2004). For their study sample of 4300 mother-infants, Khajehei et al. (Khajehei et al., 2022) found that the routine 2-week post-natal midwifery-at-home program was much less expensive than if mothers and infants had remained in hospital for two additional birth admission days ($6.6 m vs 8.6 m).

The use of clinical practice guidelines varied. In one survey study (Mateo et al., 2013) of 321 practitioners (45 % worked in community practice), 41 % of family physicians, 75 % of pediatricians, and 69 % of midwives used the American Academy of Pediatrics (AAP, 2004) or Canadian Paediatric Society (CPS) [5] guidelines to guide jaundice management. 81 % of practitioners thought the guidelines were accessible and 71 % thought they were easy to use (although this varied by practitioner type). One of the midwives in Trasancos & Horey's (Trasancos and Horey, 2024) study reported that: *'guidelines and protocols are only looked at when an issue comes up'*.

### *Variation in post-discharge care*

Four studies reported variation in post-discharge care (Mateo et al., 2013; Salem-Schatz et al., 2004; Trasancos and Horey, 2024; van der Geest et al., 2022). In one Australian qualitative study of healthcare professionals (Trasancos and Horey, 2024), post-discharge care was described as *'haphazard'* or dependent on *'competing demands'* with *'no dedicated surveillance'* measures in place: A neonatologist reported:

> *'Need better way of streamlining taking serum bilirubin levels at home. Would need to report to the registrar. Institutions vary—each hospital will have its own policies'* (Trasancos and Horey, 2024; pp.5)

The Canadian survey study by Mateo and colleagues (Mateo et al., 2013) also found that post-discharge care varied, with routine post-discharge follow-up within 72 h planned by 60 % of family physicians, 89 % of paediatricians, and 100 % of midwives ($p < 0.001$). Physicians in Salem-Schatz et al.'s (Salem-Schatz et al., 2004) qualitative study reported frustration with organising follow-up due to overloaded practice schedules and "normal hours" of operation. In an analysis of perinatal audit data from the Netherlands (van der Geest et al., 2022), there were instances where no follow-up was provided in cases of hyperbilirubinaemia.

Several suggestions were made to improve postnatal care, including an outpatient visit a day after discharge either in the office or at home,

and bilirubin screening tests for all babies at 72 h of age (Salem-Schatz et al., 2004). In one study (Trasancos and Horey, 2024), a neonatologist suggested that *'all midwives at home should perhaps carry a bilirubinometer'* and that resources, including lactation support, are needed for home visits for a minimum of 3 days before the maternal and child health nurse begin their visits. Nurses in the USA wanted to see home care as an expected standard of care and mothers suggested flexible appointments, drop-in visits, and separate office hours or waiting areas for well babies (Salem-Schatz et al., 2004).

*Type of community setting*

In Salem-Schatz et al.'s (Salem-Schatz et al., 2004) USA study, mothers differed in where follow-up should take place. Some preferred a home visit to prevent leaving the house with their newborn, or only if it was with their paediatric primary care provider or knowledgeable nurse, especially if associated with the provider. Mothers who preferred a clinic appointment said they may need assistance such as someone accompanying them and transportation.

A survey of a convenience sample of 659 mothers attending a maternal health clinic in Israel (Kaplan et al., 2019) found significant variations in attendance based on culture (attendance higher among mainstream Jewish parents (145/430 [40.5 %], $p = 0.01$) and lower among the ultra-orthodox (Haredi) (21/104 [20.2 %], $p = 0.0003$) and Arab parents (22/101[18.2 %], $p < 0.0001$), and a trend for birthweight $< 2500$ g, male sex and first delivery to increase likelihood of attendance. Reasons for non-attendance included feeling the examination was unnecessary, the belief that clinics exist for immunisation only, bad weather, maternal illness or not understanding the instruction (Kaplan et al., 2019). In a USA study (Salem-Schatz et al., 2004), mothers reported difficulties in leaving the house during the first week after discharge due to exhaustion, soreness, feeling overwhelmed, baby's eating and sleeping routine, being told not to drive for 2 weeks and fear of exposing their newborn to potentially sick children.

*Impact of community assessment*

Two studies (McClean et al., 2018; Wainer et al., 2012) found that implementing a community TcB screening program reduced the use of TSBs. In McClean et al.'s (McClean et al., 2018) study, this involved all newborns of 35 or more weeks' gestation receiving TcB screening before the newborn metabolic screen. In addition, TcB screening was integrated into daily care and was performed daily in hospital, within 4 hours before hospital discharge and at each community follow-up visit. This study found that pre-implementation there were 3844 TSB blood draws compared to 1099 TSBs post-implementation. Although there was a reduction of 71.4 % in TSB blood draws (75.3 % reduction in hospital and 49.3 % in the community), there was an increase in the total number of tests (TSB + TcB) per 1000 live births (from 1383.2 TSBs to a total of 2758.6 TSB+TcBs).

In Wainer et al.'s (Wainer et al., 2012) study, two 1-year periods were analysed. The outcomes of prospectively enrolled healthy infants ≥35 weeks gestation offered routine TcB measurements in both hospital and community settings and a historical cohort of infants initially assessed by visual inspection were compared. Wainer et al. (Wainer et al., 2012) found a significant reduction (54.9 %; $p < 0.0001$) in the incidence of severe (≥20 mg/dL, ≥342 μmol/L) initial TSB values in the community after the introduction of the TcB program. The Wainer et al. (Wainer et al., 2012) study also found that initial post-discharge assessment visits tended to be earlier during the TcB program, and more likely within 24 h (58.4 % vs 63.3 %; $P < 0.001$). Additionally there were significant increases in public health nurse visits (1.8 % to 4.0 % $p < 0.001$) and during the first week of life (1.33 vs 1.66 visits, $p < 0.01$. While neither of these studies (McClean et al., 2018; Wainer et al., 2012) had an impact on readmission rates, the use of TCBs reduced the use of phototherapy (Wainer et al., 2012); younger babies were readmitted earlier in the Wainer et al. (Wainer et al., 2012) study but not in the McClean et al. (McClean et al., 2018) study. In Wainer et al.'s (Wainer et al., 2012) study, the duration of readmission for phototherapy was also slightly reduced (24.8 ± 13.6 vs 23.2 ± 9.8 h, $p = 0.05$).

## Discussion

This systematic review is the first to synthesise the available evidence on the barriers, facilitators and experiences of assessing for neonatal jaundice in community settings in high-income countries. Six themes emerged from the thematic analysis of nine papers: 1) Communication, 2) Knowledge and skills, 3) Time and resources, 4) Variation in post-discharge care, 5) Type of community setting and 6) Impact of community screening. The findings highlight communication issues among healthcare professionals and between healthcare professionals and parents; inaccuracy of visual assessment, and delays with diagnosis. There were variations in the costs of different jaundice assessment methods (with TSB being the most expensive), post-discharge care, and the use of clinical practice guidelines to aid jaundice assessment. Education for clinicians and parents, and flexibility around parent's preferences of community setting were recommendations to improve uptake and early identification.

Similar to published reports and guidelines (NHS Race and Health Observatory, 2023; NICE, 2010), our review identified challenges for visual assessment for jaundice in terms of underestimating the severity and lack of knowledge (van der Geest et al., 2022, 2021), leading to late diagnosis and delayed treatment, particularly in babies with dark skin tones (van der Geest et al., 2021). Furthermore, while TSB is the gold standard for jaundice diagnosis (Okwundu et al., 2023), it has disadvantages. Collection of the blood sample by more specialist staff, transportation and time for processing and reporting contributed to delayed diagnosis and decision-making (Salem-Schatz et al., 2004, 2021; van der Geest et al., 2022). TSB was also much more expensive than TcB when conducted in the community (compared with in hospital), especially in rural settings (McClean et al., 2018). TcB implementation can reduce the use of invasive and costly TSBs, the number of severe TSB values, the number of babies referred to phototherapy, and the duration of readmission for phototherapy (Wainer et al., 2012). While a recent systematic review (Okwundu et al., 2023) found TcB to be a good method for detecting hyperbilirubinaemia in newborns, more research is needed to find the optimal TcB devices, threshold values for hyperbilirubinaemia, and age at which the infant should be assessed (Okwundu et al., 2023). There are also concerns around TcB not being accurate in babies with dark skin tones (Szabo et al., 2004; Taylor et al., 2015; Thomson et al., 2008; Wainer et al., 2009). Therefore, while recommendations were made for all community midwives to carry bilirubinometers (Trasancos and Horey, 2024) and that all babies should be screened at 72 h of age (Salem-Schatz et al., 2004), current evidence suggests that more research is needed to inform its optimum use.

Poor communication between healthcare professionals was a key finding in our review. Community healthcare professionals were not always informed of the baby's birth (Salem-Schatz et al., 2004), there was confusion as to who was responsible for the baby in the first few weeks of life (Salem-Schatz et al., 2004), community healthcare professionals did not always have access to the data they needed to make decisions (Salem-Schatz et al., 2004), and MCAs did not always report visual jaundice to community midwives (van der Geest et al., 2022). As professionals who had received training had higher knowledge (van der Geest et al., 2021), provider-related education sessions should be offered. Suggestions for education included risk factors for severe hyperbilirubinaemia, identifying hyperbilirubinaemia in babies with dark skin tones, and a guideline card that covers near-term infants (Salem-Schatz et al., 2004).

Healthcare professionals were unsure of the best time to speak to parents about jaundice because of its complexity and not wanting to

cause concern (Salem-Schatz et al., 2004; van der Geest et al., 2022). There were also concerns about parents not understanding clinical information (Salem-Schatz et al., 2004), with this finding supported in the wider literature amongst parents with lower levels of education (Alfouwais et al., 2018; Sutcuoglu et al., 2012). NICE (NICE, 2014) guidance highlights the importance of educating parents about jaundice in terms of providing reassurance, as well as identifying concerns. Recommendations for parent education identified within our review included support groups for new and expectant parents, breastfeeding support, education posters in newborn nurseries and providing refrigerator cards with "early warning signs" of newborn hyperbilirubinaemia (Salem-Schatz et al., 2004). Further research could focus on co-developing education-based interventions with parents from different backgrounds and assessing its impact on early identification of jaundice and readmission rates. Furthermore, as numerous issues were raised regarding inconsistencies and poor information for follow-up care (Kaplan et al., 2019) similar to other areas of healthcare (Dietrich Leurer and Misskey, 2015; Maneze et al., 2019; Snow et al., 2007), clear pathways and patient-related instructions are essential. This correlates with general challenges around health literacy and links to poorer outcomes (Feldman et al., 2024).

While there was noted variation in post-discharge care (Mateo et al., 2013; Salem-Schatz et al., 2004; Trasancos and Horey, 2024; van der Geest et al., 2022), parents also differed in whether they would prefer follow-up at home or in a community clinic (Salem-Schatz et al., 2004), with many women struggling to attend clinics for a variety of reasons (Kaplan et al., 2019; Salem-Schatz et al., 2004). In the USA in particular, reluctance to attend clinics may be a result, in part, of many families living a long way away. Mothers may also be unable to travel to clinics if for example they have had a caesarean section. Parents reported wanting more opportunities to talk to their healthcare professionals post-discharge and suggested flexible appointments, drop-in visits, an outpatient visit the day after discharge, and separate office hours or waiting areas for well babies (Salem-Schatz et al., 2004). These findings echo those by McLachlan et al. (McLachlan et al., 2008) who explored postnatal care in Australia in terms of need for greater flexibility, individualised care, and choice in service delivery.

### *Strengths and limitations*

This systematic review was carried out using structured and robust methods. The search strategy was built by the research team which includes an information specialist and was not limited by year or language of publication. Two independent researchers were involved in screening articles for inclusion, extracting data, and assessing the methodological quality of the included studies, with a third researcher consulted when needed to reach consensus.

Limitations relate to the number of studies (only nine studies) being identified in high-income countries and wide heterogeneity in terms of country, participants (infants, parents, healthcare professionals), and jaundice assessment tools used. Only two studies were rated high in terms of methodological quality (Trasancos and Horey, 2024; van der Geest et al., 2021).

Insights regarding the knowledge and ability of healthcare professionals in assessing jaundice in the community is limited to MCAs and midwives in the Netherlands conducting visual assessment (van der Geest et al., 2021; 2022). It is not known how this compares with healthcare professionals in other countries who use different methods of assessment. The only survey of current practice was in Canada (Mateo et al., 2013). As this paper is over 10 years old and rated the lowest in terms of methodological quality, its results may no longer represent current practice. This gap highlights a need for cross-cultural studies to compare and contrast existing practices in jaundice assessment, particularly among infants with dark skin tones.

Despite the evidence that babies with dark skin tones are at increased risk of hyperbilirubinaemia requiring treatment (Manning et al., 2007; Setia et al., 2002), there were very few included studies that collected participant data on ethnicity. It is therefore not possible to say how relevant the findings are to different ethnic groups. Further, as this is a review of high-income countries, the results are not generalisable to low- or middle-income countries.

## Conclusion

While jaundice is a common condition in newborn infants, if unidentified, it has the potential for far-reaching and potentially severe health implications: babies with dark skin tones are at great risk of hyperbilirubinaemia and kernicterus. This review focused on exploring experiences, barriers and facilitators to assessing for jaundice in community settings in high-income countries. Overall, only nine papers were identified, indicating a paucity of research in this area, particularly lacking studies that explored the impact of skin tone on jaundice assessment. Findings highlight communication issues, lack of training and education, and delays in diagnosis. TcBs offer promise when compared to inaccurate visual assessments and the cost and intrusive nature of TSBs, but further research is required to identify optimal TcB devices, threshold values and accuracy amongst babies with dark skin tones. There is a need to co-develop training and education for clinicians and parents and to ensure flexible, person-centred and equitable care.

## CRediT authorship contribution statement

**Lucy J Hives:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Gill Thomson:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Cath Harris:** Writing – review & editing, Writing – original draft, Data curation. **Deborah King:** Writing – review & editing. **Albert L Kwansa:** Writing – review & editing, Formal analysis, Data curation. **Aasima S Patel:** Writing – review & editing, Formal analysis, Data curation. **Janet Rennie:** Writing – review & editing, Writing – original draft, Funding acquisition, Data curation, Conceptualization. **Sarah E Seaton:** Writing – review & editing, Funding acquisition, Conceptualization. **Kylie Watson:** Writing – review & editing, Funding acquisition, Conceptualization. **Ngozi Edi-osagie:** Writing – review & editing, Funding acquisition, Conceptualization. **Cheryl Battersby:** Writing – review & editing, Funding acquisition, Conceptualization.

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## Supplementary materials

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