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# BMJ Open

## Perceptions of neonatal jaundice and evidence-based care: Interviews with 41 Australian health professionals

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**Title:** Perceptions of neonatal jaundice and evidence-based care: Interviews with 41 Australian health professionals

## **Abstract**

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality. Although severe adverse outcomes, such as hyperbilirubinaemia and kernicterus, are uncommon in high-income countries, these outcomes do occur, have enormous lifelong personal, health and social costs, and may be preventable. Evidence-based practice commonly relies on clinical guidelines however their implementation can be difficult. Five contexts affecting implementation include the clinical guidelines themselves, issues within health systems, the socio-political context, health professionals, and patients. This paper focuses on the perceptions of Australian health professionals involved in the management of neonatal jaundice.

## **Methods**

Interviews with 41 Australian health professionals from a range of disciplines and care settings using a qualitative descriptive approach and content analysis to identify themes describing experiences and perceptions.

## **Results**

Gaps in the implementation of evidence-based care to manage neonatal jaundice identified related to issues with professional boundaries, competing priorities and poor understanding of neonatal jaundice. Several health professionals felt they knew what was needed to implement best practice care through improved education and standardised policies and protocols but did not know how to make such improvements happen.

## **Conclusions**

Multiple barriers to evidence-based neonatal jaundice management create gaps in care, including in clinical guidelines. Implementation strategies for evidence-based practice need to take account of the experiences of health professionals and the challenges they face. Such strategies need to focus on improving collaboration between different disciplines for the well-being of those needing care. In

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the case of neonatal jaundice management, consideration is also needed in how to raise awareness of the importance of avoiding severe adverse outcomes, even when they might be rare, and how this might be done. Addressing issues that lead to disjointed care or poor knowledge of neonatal jaundice among health professionals is essential.

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### Strengths and Limitations of the Study Methods

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- Several health disciplines across geographical and work settings in Australia were involved in this study, providing a broad range of perspectives.
  - Limitations include the extended period for data collection and analysis, which were driven by practical constraints. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.
  - The decision not to record interviews encouraged participation. All interview scripts were verified by interviewees.
  - The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable.
  - This study presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.

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### Keywords

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Neonatal jaundice, kernicterus, evidence-based care, clinical practice guidelines, implementation science

### What is already known on this topic

Severe adverse neonatal outcomes associated with neonatal jaundice are rare in most high-income countries, but they do occur. Little is known about the perceptions of health care professionals in managing severe neonatal jaundice.

### What this study adds—

This study identifies gaps in the management of neonatal jaundice in Australia and possible ways to improve awareness and care when severe neonatal jaundice occurs.

### How this study might affect practice and policy

The study highlights the challenges to evidence-based care when issues are complex and adverse events are rare. Strengthening surveillance of adverse perinatal outcomes, including severe neonatal jaundice, would inform guideline development, associated resource decisions, and health professional training.

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**Background**

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality.(1-4) In 2016, neonatal jaundice accounted for over 1300 deaths per 100,000 livebirths and was ranked seventh among all causes of death in the early-neonatal period.(2-4) Severe adverse outcomes associated with neonatal jaundice are uncommon in high-income countries, but do occur and may be preventable, creating an ongoing challenge for health care standards.(4, 5) In Australia, the findings from a surveillance study conducted between 2010 and 2013 to determine the incidence of extreme hyperbilirubinemia (9.4 per 100,000 livebirths) and bilirubin encephalopathy (0.6 per 100 000 livebirths) in term and near-term neonates,(6) showed that at least 20 to 25 babies are affected every year. Extreme neonatal hyperbilirubinaemia can result in long-term neurological dysfunction, including brain damage and even death.(4-10)

Deficiencies in the care of jaundiced newborns have been identified as contributing to adverse outcomes.(11-14) Care deficiencies need to be minimised, particularly when adverse consequences have enormous personal costs as well as lifelong health and social costs.(14, 15) Modern health care, built on evidence-based practice, commonly relies on clinical guidelines. However, implementation of clinical guidelines can be difficult. A meta-review of 25 systematic reviews exploring the barriers and facilitators to guideline implementation(16) identified five contexts showing its complexity: the clinical guidelines themselves; the health system; the socio-political context; health professionals; and patients.

While the role of health professionals is critical to evidence-based care, their experiences in some areas of practice are largely unknown. This paper explores the perceptions of Australian health professionals involved in the management of neonatal jaundice. It is part of a mixed methods study that includes assessment of neonatal jaundice guidelines used across Australia,(17) which are based on international guidelines(18-20) that have changed little over the past decade.(17)

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## Methods

A qualitative descriptive design to explore health professionals' experiences and perspectives(21, 22) used semi-structured interviews and an interpretivist approach(23) to gain understanding of the experiences of health professionals across Australia with the care of jaundiced newborns. A purposive maximum variation sampling process was adopted.(24) Potential participants were approached in writing either directly, for those in private practice, or indirectly via institutional leaders for those working in maternity hospitals, universities, and government departments. Recruitment progressed to ensure a mix of disciplines, geographical areas and settings and continued until data saturation was achieved and no new themes emerged. Data were collected over two years, between August 2011 and December 2013. Interview topics included personal preparation and experiences of neonatal jaundice; knowledge of jaundice-related neonatal morbidity, associated policies and guidelines; and thoughts about any practice adjustments needed for better neonatal jaundice management. Interviews were conducted either face-to-face or by telephone and ranged from 20 to 120 minutes in duration (average 65 minutes). Interviews were not audio-recorded. Detailed notes were taken, including verbatim comments. Interview scripts were completed after each interview to minimise recall bias(25) and returned to participants for verification. This approach aimed to facilitate participation by recognising sensitivities with audio recordings about clinical care. A field journal was maintained to assist in validation and consistency.(26)

Following verification by participants, interview scripts were imported into NVivo qualitative research software (NVivo 10 and 12 for Mac, QSR International) for thematic content analysis.(27)

All scripts were thoroughly read and re-read to ensure accuracy, gain an overall impression of the data and to identify recurring information and variations. The preliminary analysis included coding for categories and major themes according to the different types and contexts of practice.

Preliminary codes were refined as coding progressed and as themes emerged. Themes were tested



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3 50 within and between cases to ensure integrity of the theme boundaries. Coding was checked several  
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5 51 times, including independent confirmation by two experienced researchers who read the first five  
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7 52 interviews and by a third researcher who compared final codes against a data sample. Illustrative  
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10 53 quotes were identified by discipline.  
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13 54 Reflexivity was critical as the first author intersected with the data in several ways. The study was  
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15 55 part of doctoral studies motivated by personal experience as a mother of a child diagnosed with  
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17 56 kernicterus and also as a nurse and policy and program advisor. Ezzy (2002) observed that personal  
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20 57 experience typically shapes the definition of a research problem(28) and how data are collected and  
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22 58 analysed; and so is also a data source about the research problem (2002: 153). A mindset of  
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24 59 'conscious partiality'(1999: 20)(29) was cultivated.  
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28 60 Ethics approval was given by the university Ethics Committee (FHEC11/47), and by respective health  
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30 61 and medical research committees throughout Australia. Participation was voluntary and informed  
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32 62 consent was required prior to all interviews. No one withdrew.  
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36 63 Patient and public involvement  
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39 64 The approach taken for this research was to focus on practice aspects of evidence-based care rather  
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41 65 than look at the impact of current practice on infants and families. Study participants were all health  
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43 66 professionals who provided informed consent. Plans for dissemination of results were relayed to all  
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45 67 participants and included publication in a journal and presentation in various fora.  
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48 68 **Results**  
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51 69 Participants  
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53 70 Forty-one health professionals from six broad discipline areas were interviewed (nursing [3],  
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55 71 midwifery [15], medicine [12], pathology [2], clinical education [6], and policy development [8]). The  
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57 72 12 doctors came from four different specialty areas (general practice/obstetrics, paediatrics and  
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59 73 neonatology). The majority (66%) had 10 or more years professional experience. Five participants

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74 worked across state boundaries (12%). Seven participants working in policy development also had  
75 clinical roles.

## 76 Findings

77 Two major themes and explanatory sub-themes were found (see Figure 1).

### 78 Falling through the gaps

79 This theme reflected views and reported experiences that some neonates were “slipping through  
80 the net” as a consequence of their neonatal jaundice management. Four explanatory sub-themes  
81 were associated with this theme: professional boundaries; blindness to possibility of adverse  
82 outcomes; competing professional development priorities; and unintended consequences.

#### 83 Professional boundaries

84 Gaps arising from issues related to professional boundaries were revealed across different  
85 professional groups and included limitations in knowledge and experience. Relationships and  
86 communication appeared to be affected. Knowledge gaps and lack of experience meant adverse  
87 outcomes were possible. For example, several doctors linked lack of knowledge in junior doctors as a  
88 risk, for example:

89 “...Trying to get exposure to cover all aspects of neonatal care has been an ongoing issue.  
90 Learning about neonatal jaundice is not in any formal way mandated in training of general  
91 paediatricians.” (neonatologist\_C)

92  
93 Midwives, including educators and those involved in policy development, also linked lack of  
94 adequate knowledge and clinical experience to poorer outcomes. One midwife summed up the  
95 situation this way:

96 “.... [Neonatal jaundice] is probably not managed that well.... there is the potential for it to  
97 get missed....there is no surveillance strategy.... there is a deficit in the learning.... junior  
98 doctors lack experience; they are not good at putting the picture together; they may not

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3 99 even have seen the baby....midwives are generally not able to sign pathology slips....If the  
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5 100 baby is starting to get jaundice within 24 hours – will call the paediatrician to look at the  
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7 101 baby; we monitor – see how it goes...make sure feeding is happening frequently.....If early  
8  
9 102 discharge –will home visit.....It might not be until the home visit that the midwife sees that  
10  
11 103 the baby is bright yellow.....Parents may think the baby has olive skin. Parents are not  
12  
13 104 trained to look and assess.... Guidelines and protocols are only looked at when an issue  
14  
15 105 comes up.” (Midwife\_C)  
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17 106 Professional boundaries rising from poor relationships and poor communication created potential  
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19 107 gaps in care, particularly when role conflict existed. The most common example was differences  
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21 108 between medical and midwifery paradigms, sometimes described as interventionist and non-  
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23 109 interventionist approaches. The impact was evident in descriptions of assessment approaches.  
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25 110 Midwives referred to using “intuition” or “instinct” as part of their professional assessment. In  
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27 111 contrast, medical practitioners were likely to report erring on the side of caution for both testing and  
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29 112 treating, “just in case”. As one said:  
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35 113 “...we have to do that for fear of kernicterus. At a serum bilirubin level of 310, the baby  
36  
37 114 receives treatment. It is not necessarily the right thing to do but don’t want to miss  
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39 115 pathological jaundice.” (Paediatrician\_C)  
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43 116 Tension between different professional relationships was evident in several interviews, such as  
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45 117 between pathology personnel and clinical staff:  
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49 118 “There have been specific problems measuring bilirubin for a long time; trying to get it  
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51 119 right; there is a combination of things; measurement, early discharge, lack of knowledge, lab  
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53 120 measuring delay, haemolysed samples. Lab error is unlikely; if there is a mistake it is  
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55 121 repeated.” (Pathologist\_C)  
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122 Professional boundaries affecting care were also reported within speciality groups in the same  
123 discipline, for example:

124 “There are conflicting views between the medical consultant and the paediatrician... for  
125 example in a baby with high SBR [serum bilirubin] the medical consultant will say put the  
126 baby under two lights; the paediatrician will visit later and say ‘no just use one light’.”  
127 (Midwife\_A)

128 Professional boundaries affecting communication were most evident in accounts of absent feedback  
129 when neonatal jaundice was suspected, affecting confidence among less experienced professionals  
130 when potential cases were suspected.

131 “...if you are seeing newborns babies all time, your skills are better, your assessment skills  
132 are better, when compared to midwives who only occasionally work with babies; you have a  
133 different perspective. There is a potential for over-reacting and under-reacting. I tend to  
134 overreact.” (Educator, maternal and child health/midwife\_C)

### 135 **Blindness to possibility of adverse outcomes**

136 Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in  
137 Australia. Two participants were openly cynical about the possibility of kernicterus diagnoses in  
138 Australia, including one paediatrician, who despite reporting experience with many jaundiced  
139 infants, had had no direct experience of adverse outcomes, so felt one was unlikely. Similarly, one  
140 midwife explicitly questioned whether a kernicterus diagnosis was possible in Australia. Several  
141 others commented on the rarity of severe neonatal jaundice in Australia, also raising doubts about  
142 whether serious adverse outcomes occur.

143 Knowledge of adverse outcomes associated with neonatal jaundice was not considered important in  
144 Australian conditions according to some interviewees. When talking about their clinical education,  
145 the term “kernicterus” was recalled by some midwives as a “scary thing” or reportedly mentioned

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146 “in passing”. Despite several comments about higher proportions of Asian women readmitted with  
147 jaundiced babies, only five participants (two paediatricians, a neonatologist, midwife and neonatal  
148 nursing educator), considered the needs of genetic diversity and ongoing population changes, aware  
149 of a clinical trial conducted in one health service.

150 Very few participants recognised the increased risk for First Nation Australians. One paediatrician  
151 who worked in an area with a higher proportion of First Nation residents and those with Asian  
152 backgrounds, questioned the association with skin colour, commenting:

153 “One cannot make assumptions about ethnic heritage; there has been much exchange of  
154 genetic material over the years. Pigmentation is not fully developed in the first few weeks of  
155 life.” (Paediatrician\_A)

156 **Competing professional development priorities**

157 Almost all health professionals acknowledged difficulties in keeping abreast of research evidence;  
158 some felt individuals were responsible to keep up-to-date, but most relied on others to make  
159 research information available.

160 “I don’t go looking for [information, literature] ” (Midwife\_B)

161 Participants who felt unable to keep up with research, also talked about other priorities, lack of  
162 access to resources or the size of the challenge:

163 “Keeping up to date with research is difficult. A significant number of midwives don’t do it  
164 well. If outside the system, it is difficult, if not enrolled in University. How many journals can  
165 you subscribe to? It costs money. You rely on Google. You give up. Access is difficult.

166 Enrolling in University costs money and you need time” (Midwifery educator/consultant\_C)

167 Most participants agreed that neonatal jaundice was one of many conditions that health  
168 professionals need to know about. Several acknowledged lack of understanding of normal  
169 physiology or differences between physiological and pathological jaundice. Overall, professional  
170 development opportunities on neonatal jaundice care were limited.

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## Unintended consequences

Systemic issues within service delivery and organisations revealed involved unintended consequences, such as the absence of mechanisms to document adverse effects. Some participants pointed out that without such information measuring impact is difficult. Participants cognisant of potential consequences remarked:

“One may not know the outcome of severe neonatal jaundice for years. Hearing loss may be evident within hours.” (Pathologist\_D&F)

“Common reasons for readmission are G6PD, ABO incompatibility, dehydration, bruising. There is less awareness around these. The number of babies readmitted is not coded as separate. It is not easy to get this information.” (Neonatologist\_E)

Many interviewees commented on the potential cost of testing, which was commonly considered in terms of over-testing and over-treatment. One participant said:

“You would need to test every parent and child. Test fathers, test cord blood. Per baby it would be \$150 extra assuming 200,000 babies born per year – there would not be much benefit.” (Paediatrician\_C)

In contrast, another participant felt it would be cheaper to test every baby “as then the health service cannot be sued....”. Several doctors and a pathologist raised the potential costs associated with one missed case.

Early discharge of mothers and babies was commonly identified as a potential problem for neonatal jaundice identification. All participants working in hospital postnatal wards identified early discharge as a barrier to developing better clinical knowledge:

“There is a concern about early discharge. It is a problem in Australia. It seems greater [than in other countries]. Our women get kicked out. Monitoring is variable across Australia. What is the monitoring process?” (Neonatologist\_C)

Issues arising from early discharge included variability in post-discharge care, where neonatal jaundice management was variously described as “haphazard” or dependent on “competing

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3 197 demands” with “no dedicated surveillance” measures in place. While one neonatologist described a  
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5 198 robust community system, numerous others, including other neonatologists, did not concur:  
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7 199 “Need better way of streamlining taking serum bilirubin levels at home. Would need to  
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9 200 report to the registrar. All midwives at home should perhaps carry a bilirubinometer.  
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11 201 Institutions vary – each hospital will have its own policies. .... Need resources for daily home  
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13 202 visits for a minimum of three days until the maternal and child health nurse kicks in; need  
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15 203 lactation support.” (Neonatologist\_C)  
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18 204 Contributing to uncertainty about patient care trajectories was growing reliance on a casualised  
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20 205 workforce, particularly in midwifery, which was seen to affect skill and knowledge development:  
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22 206 “Midwives, we are reliant on them for recognising and assessing; they are a mixed bunch;  
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24 207 quite a number do shifts in post-natal ward. They are semi-deskilling themselves. Not  
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26 208 keeping up to date. They occasionally take a while to properly communicate regarding  
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28 209 jaundiced cases.” (Paediatrician\_C)  
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33 210 Poor knowledge of neonatal jaundice among health professionals also affects communication with  
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35 211 parents about the condition. Some participants pointed out that no specific information for parents  
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37 212 existed while others were concerned not to overwhelm parents with more information than needed.  
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41 213 **We know what should happen – but how?**  
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43 214 The second major theme was the perception among participants that while they knew what was  
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45 215 required to improve care, they were unsure how to achieve those changes.  
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48 216 **Improvements in education and training**  
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50 217 Almost all participants expressed needs for better education, particularly for midwives and junior  
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52 218 doctors and parents. Several participants suggested that links between curriculum, guidelines and  
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54 219 clinical practice were missing:  
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56 220 “There was a little bit of education around neonatal jaundice during medical training; not  
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58 221 thorough; not much at all. It should be covered better especially for GP obstetricians. My  
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general knowledge is not great about neonatal jaundice. There is a midwife educator.....

maybe should have a bigger role. This may include keeping in touch with current research

publications; to let us know what is out there.” (GP/Obstetrician\_C)

Guidelines were frequently portrayed as ineffective tools for evidence-based care. The development and update of clinical guidelines was described as time-consuming. Several participants reported that guidelines were not included in their professional training and were considered difficult to navigate and not specific enough to be useful.

“Guidelines. Don’t use them, don’t look at these.” (Midwifery educator\_C)

“We need concrete guidelines around when to take SBR [serum bilirubin], for example if the jaundice is below the belly button, you need to do a blood test. Need to take away subjectivity.” (Educator/maternal and child health coordinator/midwife\_C)

### **Standardised policies and protocols**

Most participants described policies and processes relating to neonatal jaundice management as variable and viewed as significant barriers to achieving necessary changes. Underpinning concerns were inconsistent or confusing language. Several participants pointed to examples of how different types of jaundice were described and assessed. For example, “clinical jaundice” was used to describe jaundice requiring a blood test and “jaundice” used when “severe jaundice” meant. Conflation created confusion—and, in the views of some participants—diminished the importance of severe bilirubin among clinicians.

While calls for consistency in neonatal jaundice management came from across discipline areas, all conceded that reaching agreement was difficult. Some health professionals felt there was already multidisciplinary collaboration in policy and guideline development, while others believed such collaboration to be missing. Challenges included a “them-and-us” mindset, including between tertiary centres and smaller services, and even siloed approaches within tertiary centres:



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The wordiness of guidelines was frequently criticised. Poor accessibility exacerbated dissatisfaction. Participants using guideline websites found navigation difficult. The majority felt current guidelines needed to be reviewed, updated, or in some views, developed. Some called for more prescriptive guidelines “to rule out grey areas”.

“Guidelines – they are not easy to find; website is not intuitive, guidelines are under “metabolic” (section). At 3am in the morning, when everyone is tired, (guidelines are) hard to find. On-line - so many guidelines. Use most recent but many are out of date.”  
(Paediatrician\_A)

**Discussion**

In looking at the experiences of Australian health professionals with neonatal jaundice management, challenges with implementing evidence-based care have been revealed. Several gaps in effective implementation were identified alongside feelings of inability to enact effective change. These issues are likely to apply beyond neonatal jaundice management to the wider use of evidence-based care. Four of five contexts relevant to clinical practice guideline implementation identified in the meta-review exploring barriers and facilitators,(16) were evident in this study: the clinical guidelines themselves, the health system, the socio-political context and health professionals. This study also identified particular challenges for evidence-based care when adverse events are rare. Consistent with the most frequently mentioned barrier to guideline implementation in the meta-review(16) were clinical guidelines themselves, particularly with lack of clarity. Other issues such as problems with credibility and day-to-day practice feasibility were also present and appear to be related to inconsistency, lack of standardisation, and unnecessary wordiness. Poor accessibility to guidelines exacerbated dissatisfaction and fuelled scepticism about guideline usefulness.

Barriers identified in the health system context in the meta-review, lack of time, resources, and specialised personnel(16) were also raised in this study. Two other health system developments were linked to possible unintended consequences for neonatal jaundice management. Early discharge practices were directly attributed to creating difficulties for timely diagnosis. Participants pointed out that in the context of early discharge greater need for parent awareness of neonatal jaundice exists. Predictors of discharge 'readiness' explored in a US study involving 185 mothers, suggest that potential problems could be ameliorated by good pre-discharge education practices, although education depends on what, and how, nurses are able to teach mothers before leaving hospital.(30) Workforce casualisation was another health system issue identified as a potential barrier to good care for midwives in particular, reducing opportunities to acquire and reinforce neonatal jaundice knowledge.

The political and social context identified in the meta-review included barriers such as absent or poor leadership, teamwork difficulties; and lack of agreement between colleagues around guideline implementation.(16) In this study, issues of leadership and implementation agreement were also raised although interprofessional conflict was more frequently reported. Problems with interprofessional boundaries in health care can be found across the literature. For example, professional boundaries have impeded attempts to deliver best practice in unintended or unexpected ways. In Wales, an attempt to reduce unnecessary childbirth interventions by promoting midwife-led care using a clinical pathway found stricter boundary delineation actually reduced the scope of midwifery practice.(31) Whereas in Australia, inter-professional differences affected communication and information transfer in study looking at child and family health services.(32)

Key to resolving professional conflicts is understanding that divergent perceptions do arise between disciplines, and even within the same discipline. This was evident in this study where the inclusion of several discipline groups found conflicting paradigms guiding care. This is not unique to Australia or to neonatal jaundice management. In a large Swedish university hospital study, existing power

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3 293 relations impeded effective professional teamwork.(33) Awareness of the interrelationships  
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5 294 between professions, particularly when professional knowledge and work overlap, needs  
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7 295 consideration in planning care and in developing guidelines. Interprofessional relationship issues,  
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9 296 characterised by competition and conflict, seem central to professional identity.(34) They need  
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11 297 ongoing attention. Interdependent professions can experience constant conflict when continuous  
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13 298 engagement related to expert labour and jurisdictional disputes exist. Resolution, when it does  
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15 299 occur, tends to be temporary and followed by renewed disturbances.(34)  
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20 300 Gaps in neonatal jaundice knowledge were acknowledged in this study and in other studies and  
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22 301 other countries. For example, in the USA, a cross-sectional study of paediatricians(35) found  
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24 302 significant uncertainty in relation to identifying risk factors and using diagnostic approaches to  
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26 303 manage neonatal jaundice. Congruent findings were also found in a root-cause analysis of 125 full-  
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28 304 term infants with acute bilirubin encephalopathy voluntarily reported to the Pilot USA Kernicterus  
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30 305 Registry (1992 to 2004), where the progression to hazardous bilirubin levels was attributed to the  
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32 306 inability of multiple health professionals across multiple sites to identify at-risk infants or to manage  
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34 307 severe hyperbilirubinemia in a timely way.(36)  
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39 308 An important finding of this study, unrelated to previous studies in this area, relates to particular  
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41 309 challenges when adverse events are rare. Low case frequency may give clinicians false confidence  
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43 310 that processes are working. The incidence of severe neonatal outcomes arising from extreme  
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45 311 neonatal hyperbilirubinemia in Australia, when reported by clinicians, is around 10 per 100 000 live  
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47 312 births.(6) While international comparisons are difficult due to definitional differences, including  
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49 313 serum cut-off levels, gestational age ranges, and methods of data collection, a Swedish study that  
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51 314 identified cases of kernicterus (bilirubin encephalopathy) through medical records, found almost half  
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53 315 were most likely avoidable. These were attributed to failure to adhere to best practice, including  
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55 316 untimely or no bilirubin screening, misinterpretation of bilirubin levels, and delayed or failure to  
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57 317 initiate treatment.(37) That some health professionals in this study dismissed the possibility of  
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severe adverse outcomes in Australia is concerning, particularly as lack of awareness of the possibility of poor outcomes can be the most significant barrier to improving patient safety.(38) The absence of ongoing reporting of all adverse neonatal outcomes, including severe neonatal jaundice, appears to be critical. In the absence of adverse outcome data, there is little opportunity for health professionals to build knowledge or to make reasonable cost-benefit judgements.

### **Strengths and Limitations**

Both strengths and limitations are present. Several health disciplines across geographical and work settings in Australia were involved, providing a broad range of perspectives. Limitations include the extended period for data collection and analysis, which were driven by practical constraints. The study was conducted over a staggered period, somewhat mirroring the process of guideline development. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.(17) The slow pace of analysis also gave time for reflection. The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable. The decision not to record interviews may be viewed by some as a limitation but also encouraged participation and all scripts were verified by interviewees. Interview scripts written directly after interviews have been shown to have similar quality to audio-recorded transcripts.(25) Despite its limitations, this paper presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.(39)

### **Conclusion**

Multiple barriers exist in evidence-based care related to neonatal jaundice management. Gaps in care exist as clinical guidelines alone are not sufficient to support health professionals deliver evidence-based care in the complex contexts in which they work. Implementation strategies for evidence-based practice need to take account of health professionals' experiences and the challenges they face. Implementation strategies for neonatal jaundice management need to

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343 consider how to raise awareness of the importance of avoiding severe adverse outcomes, despite  
344 their rarity, the consequences are devastating. Addressing issues that lead to disjointed care or poor  
345 knowledge of neonatal jaundice is essential. Gaps in evidence-based practice arise even when  
346 clinical guidelines exist, and health professionals do not know how to address them.

347 **The authors declare that they have no conflict of interest.**

348 **No external funding was received for this research.**

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8 **Figure 1-** Analysis of 41 interviews with health professionals: two major themes and explanatory  
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Figure 1: Analysis of 41 interviews with health professionals: two major themes and explanatory sub-themes.



209x296mm (200 x 200 DPI)

## Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

### Title and abstract

<b>Title</b>	Perceptions of neonatal jaundice and evidence-based care: Interviews with 41 Australian health professionals
<b>Abstract</b>	Summary of key elements using required abstract format

### Introduction

<b>Problem formulation</b>	Page 4/Lines 2-21
<b>Purpose or research question</b>	Page 4/Lines 21-22

### Methods

<b>Qualitative approach and research paradigm</b>	Page 5/Lines 26-27
<b>Researcher characteristics and reflexivity</b>	Page 6/Lines 54-59.
<b>Context</b>	Page 5/ Lines 26-38 Page 6/ Line 63-67 (patient and public involvement)
<b>Sampling strategy</b>	Page 5// Lines 28-33
<b>Ethical issues pertaining to human subjects -</b>	Page 6/ Lines 60-62
<b>Data collection methods</b>	Page 5/Lines 26-28; 33-37
<b>Data collection instruments and technologies</b>	Page 5/Lines 37-43
<b>Units of study</b>	Page 7/Lines 70-75
<b>Data processing</b>	Page 5/Lines 44-47
<b>Data analysis</b>	Pages 5/Lines 47-50
<b>Techniques to enhance trustworthiness</b>	Page 5/Lines 39-43 Pages 6/Lines 50-53

### Results/findings

<b>Synthesis and interpretation</b>	Page 7/ Line 77 and Figure 1
<b>Links to empirical data</b>	Pages 7-17 – cited throughout

### Discussion

<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b>	Pages 14-17/Lines 263-322
<b>Limitations</b>	Page 17/Lines 325-333

### Other

<b>Conflicts of interest</b>	Page 18 - None known - Line 347
<b>Funding</b>	Page 18 -No external funding – Line 348

# BMJ Open

## Experiences with neonatal jaundice management in hospitals and the community: Interviews with Australian health professionals.

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Secondary Subject Heading:	Evidence based practice, Medical education and training, Qualitative research
Keywords:	NEONATOLOGY, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, EDUCATION & TRAINING (see Medical Education & Training)

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**Title:** Experiences with neonatal jaundice management in hospitals and the community: Interviews with Australian health professionals

## Abstract

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality. Although severe adverse outcomes, such as hyperbilirubinaemia and kernicterus, are uncommon in high-income countries, these outcomes do occur, have enormous lifelong personal, health and social costs, and may be preventable. Evidence-based practice commonly relies on clinical guidelines however their implementation can be difficult. Implementation of neonatal jaundice care has been adversely affected by issues with professional boundaries, competing professional priorities and poor understanding of neonatal jaundice. This paper focuses on the perceptions and experiences of Australian health professionals involved in the management of neonatal jaundice.

## Methods

Using a qualitative descriptive approach, semi-structured interviews were undertaken to gain understanding of the experiences of health professionals in Australia across the scope of care for jaundiced newborns through an interpretivist approach and to identify possible gaps in the delivery of evidence-based care. Health professionals from a range of disciplines and care settings were recruited by purposive maximum variation sampling. Interviews were conducted face-to-face or by telephone with detailed notes taken and a field journal maintained. Interview scripts were verified by participants and imported into NVivo software. Data were analysed for major themes according to type and contexts of practice.

## Results

Forty-one health professionals from six broad discipline areas were interviewed. Two major themes and explanatory sub-themes were found. The first theme, *Falling through the gaps*, highlighted gaps in evidence-based care, as described by four explanatory sub-themes: professional boundaries; blindness to possibility of adverse outcomes; competing professional development priorities; and unintended consequences.

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The second major theme, *We know what should happen – but how?*, described participant perceptions that it was known what was required to improve care but how to achieve such changes was unclear. The two sub-themes are: improvements in education and training; and standardised policies and protocols.

**Conclusions**

Multiple barriers to the provision of evidence-based care related to neonatal jaundice management are experienced by health professionals in Australia. Clinical guidelines are not sufficient to support health professionals deliver evidence-based care in the complex contexts in which they work. Implementation strategies for evidence-based practice need to take account of the experiences of health professionals and the challenges they face. Such strategies need to focus on improving collaboration between different disciplines for the well-being of those needing care. In the case of neonatal jaundice management, consideration is also needed in how to raise awareness of the importance of avoiding severe adverse outcomes, even when they might be rare, and how this might be done. Addressing issues that lead to disjointed care or poor knowledge of neonatal jaundice among health professionals is essential.



**Strengths and Limitations of the Study Methods**

- Several health disciplines across geographical and work settings in Australia were involved in this study, providing a broad range of perspectives.
- Limitations include the extended period for data collection and analysis, which were driven by practical constraints. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.
- The decision not to record interviews encouraged participation. All interview scripts were verified by interviewees.

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- The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable.
- This study presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.

### Keywords

Neonatal jaundice, kernicterus, evidence-based care, clinical practice guidelines, implementation science

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**Background**

Worldwide, neonatal jaundice accounts for considerable morbidity and mortality.(1-4) In 2016, neonatal jaundice accounted for over 1300 deaths per 100,000 livebirths and was ranked seventh among all causes of death in the early-neonatal period.(2-4) Severe adverse outcomes associated with neonatal jaundice are uncommon in high-income countries, but do occur and may be preventable, creating an ongoing challenge for health care standards.(4, 5) In Australia, the findings from a surveillance study conducted between 2010 and 2013 to determine the incidence of extreme hyperbilirubinemia (9.4 per 100,000 livebirths) and bilirubin encephalopathy (0.6 per 100 000 livebirths) in term and near-term neonates,(6) showed that at least 20 to 25 babies are affected every year. Extreme neonatal hyperbilirubinaemia can result in long-term neurological dysfunction, including brain damage and even death.(4-10)

Deficiencies in the care of jaundiced newborns have been identified as contributing to adverse outcomes.(11-14) Care deficiencies need to be minimised, particularly when adverse consequences have enormous personal costs as well as lifelong health and social costs.(14, 15) Modern health care, built on evidence-based practice, commonly relies on clinical guidelines, that are developed from the best available evidence, even when such evidence is weak. Implementation of clinical guidelines can be difficult. A meta-review of 25 systematic reviews exploring the barriers and facilitators to guideline implementation(16) identified five contexts showing its complexity: the clinical guidelines themselves; the health system; the socio-political context; health professionals; and patients.

While the role of health professionals is critical to evidence-based care, their experiences in some areas of practice are largely unknown. The focus of this paper is the management of neonatal jaundice, which relies on the use of clinical guidelines, and where rare, severe, adverse outcomes do occur. This study aims to explore health professionals' experiences and perspectives of neonatal jaundice management in Australia to identify possible gaps in the delivery of evidence-based care. This study is part of a mixed methods study that includes assessment of neonatal jaundice guidelines

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used across Australia(17). These guidelines in Australia are based on international guidelines(18-20) and, as shown in a recent comparative review(17), have changed little over the past decade.

## Methods

Using a qualitative descriptive design (21, 22), semi-structured interviews were undertaken to gain understanding of the experiences of health professionals in Australia across the scope of care for jaundiced newborns through an interpretivist approach (23) and to identify possible gaps in the delivery of evidence-based care. We considered evidence-based care to comprise the three elements nominated by Sackett (1996)(24): use of the best available research evidence; application of clinical expertise; and consideration of patient “predicaments, rights and preferences”(24).

A purposive maximum variation sampling process was adopted.(25) Potential participants were approached in writing either directly, for those in private practice, or indirectly via institutional leaders for those working in maternity hospitals, universities, and government departments. These leaders identified potential participants associated with neonatal jaundice care and forwarded information to them about the study, including consent forms to complete. Potential participants approached directly, including general practitioners, obstetricians, paediatricians, midwives in private practice and maternal and child health nurses, were also sent this information. It was anticipated that approximately 40 participants would be needed based on five participants from each State and Territory and the number of disciplines approached. Recruitment progressed to ensure the desired mix of disciplines, geographical areas and settings and continued until data saturation was achieved and no new themes emerged. (26) Data were collected over two years, between August 2011 and December 2013. Interview topics (see Supplementary material) included personal preparation and experiences of neonatal jaundice; knowledge of jaundice-related neonatal morbidity, associated policies and guidelines; and thoughts about any practice adjustments needed for better neonatal jaundice management. Interviews were conducted either face-to-face or by

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50 telephone after participants provided written informed consent and ranged from 20 to 120 minutes

51 in duration (average 65 minutes). Interviews were not audio-recorded. Detailed notes were taken,

52 including verbatim comments. Interview scripts were completed after each interview to minimise

53 recall bias(27) and returned to participants for verification. This approach aimed to facilitate

54 participation by recognising sensitivities with audio recordings about clinical care. A field journal was

55 maintained to assist in validation and consistency.(28)

56 Following verification by participants, interview scripts were imported into NVivo qualitative

57 research software (NVivo 10 and 12 for Mac, QSR International) for thematic content analysis.(29)

58 All scripts were thoroughly read and re-read to ensure accuracy, gain an overall impression of the

59 data and to identify recurring information and variations. The preliminary analysis included coding

60 for categories and major themes according to the different types and contexts of practice.

61 Preliminary codes were refined as coding progressed and as themes emerged. Themes were tested

62 within and between cases to ensure integrity of the theme boundaries. Coding was checked several

63 times, including independent confirmation by two experienced researchers who read the first five

64 interviews and by a third researcher who compared final codes against a data sample. Illustrative

65 quotes were identified by discipline.

66 Reflexivity was critical as the first author intersected with the data in several ways. The study was

67 part of doctoral studies motivated by personal experience as a mother of a child diagnosed with

68 kernicterus and also as a nurse and policy and program advisor. Ezzy (2002) observed that personal

69 experience typically shapes the definition of a research problem(30) and how data are collected and

70 analysed; and so is also a data source about the research problem (2002: 153). A mindset of

71 'conscious partiality'(1999: 20)(31) was cultivated.

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Ethics approval was given by the university Ethics Committee (FHEC11/47), and by respective health and medical research committees throughout Australia. Participation was voluntary and informed consent was required prior to all interviews. No one withdrew.

## Patient and public involvement

There was no patient involvement in the study. The approach taken for this research was to focus on practice aspects of evidence-based care rather than look at the impact of current practice on infants and families. Study participants were all health professionals who provided written informed consent. Plans for dissemination of results were relayed to all participants and included publication in a journal and presentation in various fora.

## Results

### Participants

Forty-one registered health professionals working with jaundiced newborns in some way, were interviewed. Participants came from six broad discipline areas (nursing [3], midwifery [15], medicine [12], pathology [4], clinical education [6], and policy development [8]), and worked in a range of settings.

The 12 doctors came from four different specialty areas (general practice/obstetrics, paediatrics and neonatology). The nurses were involved in neonatal care, both within the hospital and in the community. The midwives worked in hospital and/or private practice, involving homebirth and/or postnatal care. The clinical education group included maternal and child health, neonatal care, and midwifery care. The majority of participants (66%) had 10 or more years professional experience. Five participants worked across state boundaries (12%). Seven participants working in policy development also had clinical roles. All eight participants in this group were employed by health organisations and were engaged specifically in the development of neonatal jaundice policy.

## Findings

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Two major themes and explanatory sub-themes were found: Figure 1.

**Falling through the gaps**

This theme reflected views and reported experiences that some neonates were “slipping through the net” as a consequence of their neonatal jaundice management. Four explanatory sub-themes were associated with this theme: professional boundaries; blindness to possibility of adverse outcomes; competing professional development priorities; and unintended consequences.

**Professional boundaries**

Gaps arising from issues related to professional boundaries were revealed across different professional groups and included limitations in knowledge and experience. Relationships and communication appeared to be affected. Knowledge gaps and lack of experience meant adverse outcomes were possible. For example, several doctors linked lack of knowledge in junior doctors as a risk, for example:

“...Trying to get exposure to cover all aspects of neonatal care has been an ongoing issue. Learning about neonatal jaundice is not in any formal way mandated in training of general paediatricians.” (neonatologist\_C)

Midwives, including educators and those involved in policy development, also linked lack of adequate knowledge and clinical experience to poorer outcomes. One midwife summed up the situation this way:

“.... [Neonatal jaundice] is probably not managed that well.... there is the potential for it to get missed....there is no surveillance strategy.... there is a deficit in the learning.... junior doctors lack experience; they are not good at putting the picture together; they may not even have seen the baby....midwives are generally not able to sign pathology slips....If the baby is starting to get jaundice within 24 hours – will call the paediatrician to look at the baby; we monitor – see how it goes...make sure feeding is happening frequently.....If early discharge –will home visit.....It might not be until the home visit that the midwife sees that

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2  
3 121 the baby is bright yellow.....Parents may think the baby has olive skin. Parents are not  
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5 122 trained to look and assess.... Guidelines and protocols are only looked at when an issue  
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7 123 comes up.” (Midwife\_C)  
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10 124 Professional boundaries rising from poor relationships and poor communication created potential  
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12 125 gaps in care, particularly when role conflict existed. The most common example was differences  
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14 126 between medical and midwifery paradigms, sometimes described as interventionist and non-  
15  
16 127 interventionist approaches. The impact was evident in descriptions of assessment approaches.  
17  
18 128 Midwives referred to using “intuition” or “instinct” as part of their professional assessment. In  
19  
20 129 contrast, medical practitioners were likely to report erring on the side of caution for both testing and  
21  
22 130 treating, “just in case”. As one said:  
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24 131 “...we have to do that for fear of kernicterus. At a serum bilirubin level of 310, the baby  
25  
26 132 receives treatment. It is not necessarily the right thing to do but don’t want to miss  
27  
28 133 pathological jaundice.” (Paediatrician\_C)  
29  
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31  
32 134 Tension between different professional relationships was evident in several interviews, such as  
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34 135 between pathology personnel and clinical staff:  
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37 136 “There have been specific problems measuring bilirubin for a long time; trying to get it  
38  
39 137 right; there is a combination of things; measurement, early discharge, lack of knowledge, lab  
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41 138 measuring delay, haemolysed samples. Lab error is unlikely; if there is a mistake it is  
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43 139 repeated.” (Pathologist\_C)  
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45  
46 140 Professional boundaries affecting care were also reported within speciality groups in the same  
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48 141 discipline, for example:  
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50  
51 142 “There are conflicting views between the medical consultant and the paediatrician... for  
52  
53 143 example in a baby with high SBR [serum bilirubin] the medical consultant will say put the  
54  
55 144 baby under two lights; the paediatrician will visit later and say ‘no just use one light’.”  
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58 145 (Midwife\_A)  
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3 146 Professional boundaries affecting communication were most evident in accounts of absent feedback  
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5 147 when neonatal jaundice was suspected, affecting confidence among less experienced professionals  
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7 148 when potential cases were suspected.  
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11 149 “...if you are seeing newborns babies all time, your skills are better, your assessment skills  
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13 150 are better, when compared to midwives who only occasionally work with babies; you have a  
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15 151 different perspective. There is a potential for over-reacting and under-reacting. I tend to  
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17 152 overreact.” (Educator, maternal and child health/midwife\_C)  
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20  
21 153 **Blindness to possibility of adverse outcomes**  
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23 154 Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in  
24  
25 155 Australia. Two participants were openly cynical about the possibility of kernicterus diagnoses in  
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27 156 Australia, including one paediatrician, who despite reporting experience with many jaundiced  
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29 157 infants, had had no direct experience of adverse outcomes, so felt one was unlikely. Similarly, one  
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31 158 midwife explicitly questioned whether a kernicterus diagnosis was possible in Australia. Several  
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33 159 others commented on the rarity of severe neonatal jaundice in Australia, also raising doubts about  
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35 160 whether serious adverse outcomes occur.  
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40 161 Knowledge of adverse outcomes associated with neonatal jaundice was not considered important in  
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42 162 Australian conditions according to some interviewees. When talking about their clinical education,  
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44 163 the term “kernicterus” was recalled by some midwives as a “scary thing” or reportedly mentioned  
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46 164 “in passing”. Despite several comments about higher proportions of Asian women readmitted with  
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48 165 jaundiced babies, only five participants (two paediatricians, a neonatologist, midwife and neonatal  
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50 166 nursing educator), considered the needs of genetic diversity and ongoing population changes.  
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54 167 Very few participants recognised the increased risk for First Nation Australians. One paediatrician  
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56 168 who worked in an area with a higher proportion of First Nation residents and those with Asian  
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58 169 backgrounds, questioned the association with skin colour, commenting:  
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“One cannot make assumptions about ethnic heritage; there has been much exchange of genetic material over the years. Pigmentation is not fully developed in the first few weeks of life.” (Paediatrician\_A)

### **Competing professional development priorities**

Almost all health professionals acknowledged difficulties in keeping abreast of research evidence; some felt individuals were responsible to keep up-to-date, but most relied on others to make research information available.

“I don’t go looking for [information, literature] ” (Midwife\_B)

Participants who felt unable to keep up with research, also talked about other priorities, lack of access to resources or the size of the challenge:

“Keeping up to date with research is difficult. A significant number of midwives don’t do it well. If outside the system, it is difficult, if not enrolled in University. How many journals can you subscribe to? It costs money. You rely on Google. You give up. Access is difficult.

Enrolling in University costs money and you need time” (Midwifery educator/consultant\_C)

Most participants agreed that neonatal jaundice was one of many conditions that health professionals need to know about. Several acknowledged lack of understanding of normal physiology or differences between physiological and pathological jaundice. Overall, professional development opportunities on neonatal jaundice care were limited.

### **Unintended consequences**

Systemic issues within service delivery and organisations revealed unintended consequences, such as the absence of mechanisms to document adverse effects. Some participants pointed out that without such information measuring impact is difficult. Participants cognisant of potential consequences remarked:

“One may not know the outcome of severe neonatal jaundice for years. Hearing loss may be evident within hours.” (Pathologist\_D&F)

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3 195 “Common reasons for readmission are G6PD, ABO incompatibility, dehydration, bruising.  
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5 196 There is less awareness around these. The number of babies readmitted is not coded as  
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8 197 separate. It is not easy to get this information.” (Neonatologist\_E)  
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10 198 Many interviewees commented on the potential cost of testing, which was commonly considered in  
11  
12 199 terms of over-testing and over-treatment. One participant considered the prevention of severe  
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14 200 neonatal jaundice attributed to ABO incompatibility and said:  
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16 201 “You would need to test every parent and child. Test fathers, test cord blood. Per baby it  
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18 202 would be \$150 extra assuming 200,000 babies born per year – there would not be much  
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21 203 benefit.” (Paediatrician\_C)  
22  
23 204 In contrast, another participant felt it would be cheaper to test every baby “as then the health  
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25 205 service cannot be sued....”. Several doctors and a pathologist raised the potential costs associated  
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27 206 with one missed case.  
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29 207 Early discharge of mothers and babies was commonly identified as a potential problem for neonatal  
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31 208 jaundice identification. All participants working in hospital postnatal wards identified early discharge  
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33 209 as a barrier to developing better clinical knowledge:  
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36 210 “There is a concern about early discharge. It is a problem in Australia. It seems greater [than  
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38 211 in other countries]. Our women get kicked out. Monitoring is variable across Australia. What  
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40 212 is the monitoring process?” (Neonatologist\_C)  
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43 213 Issues arising from early discharge included variability in post-discharge care, where neonatal  
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45 214 jaundice management was variously described as “haphazard” or dependent on “competing  
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47 215 demands” with “no dedicated surveillance” measures in place. While one neonatologist described a  
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49 216 robust community system, numerous others, including other neonatologists, did not concur:  
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52 217 “Need better way of streamlining taking serum bilirubin levels at home. Would need to  
53  
54 218 report to the registrar. All midwives at home should perhaps carry a bilirubinometer.  
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57 219 Institutions vary – each hospital will have its own policies. .... Need resources for daily home  
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visits for a minimum of three days until the maternal and child health nurse kicks in; need  
lactation support.” (Neonatologist\_C)

Contributing to uncertainty about patient care trajectories was growing reliance on a casualised  
workforce, particularly in midwifery, which was seen to affect skill and knowledge development:  
“Midwives, we are reliant on them for recognising and assessing; they are a mixed bunch;  
quite a number do shifts in post-natal ward. They are semi-deskilling themselves. Not  
keeping up to date. They occasionally take a while to properly communicate regarding  
jaundiced cases.” (Paediatrician\_C)

Poor knowledge of neonatal jaundice among health professionals also affects communication with  
parents about the condition. Some participants pointed out that no specific information for parents  
existed while others were concerned not to overwhelm parents with more information than needed.

### **We know what should happen – but how?**

The second major theme was the perception among participants that while they knew what was  
required to improve care, they were unsure how to achieve those changes.

### **Improvements in education and training**

Almost all participants expressed needs for better education, particularly for midwives and junior  
doctors and parents. Several participants suggested that links between curriculum, guidelines and  
clinical practice were missing:

“There was a little bit of education around neonatal jaundice during medical training; not  
thorough; not much at all. It should be covered better especially for GP obstetricians. My  
general knowledge is not great about neonatal jaundice. There is a midwife educator.....  
maybe should have a bigger role. This may include keeping in touch with current research  
publications; to let us know what is out there.” (GP/Obstetrician\_C)

Guidelines were frequently portrayed as ineffective tools for evidence-based care. The development  
and update of clinical guidelines was described as time-consuming. Several participants reported

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3 245 that guidelines were not included in their professional training and were considered difficult to  
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5 246 navigate and not specific enough to be useful.  
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7 247 “Guidelines. Don’t use them, don’t look at these.” (Midwifery educator\_C)  
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9 248 “We need concrete guidelines around when to take SBR [serum bilirubin], for example if the  
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11 249 jaundice is below the belly button, you need to do a blood test. Need to take way  
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13 250 subjectivity.” (Educator/maternal and child health coordinator/midwife\_C)  
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17 251 **Standardised policies and protocols**

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19 252 Most participants described policies and processes relating to neonatal jaundice management as  
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21 253 variable and viewed as significant barriers to achieving necessary changes. Underpinning concerns  
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23 254 were inconsistent or confusing language. Several participants pointed to examples of how different  
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25 255 types of jaundice were described and assessed. For example, “clinical jaundice” was used to describe  
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27 256 jaundice requiring a blood test and “jaundice” used when “severe jaundice” meant. Conflation  
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29 257 created confusion—and, in the views of some participants—diminished the importance of severe  
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31 258 bilirubin among clinicians.  
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36 259 While calls for consistency in neonatal jaundice management came from across discipline areas, all  
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38 260 conceded that reaching agreement was difficult. Some health professionals felt there was already  
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40 261 multidisciplinary collaboration in policy and guideline development, while others believed such  
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42 262 collaboration to be missing. Challenges included a “them-and-us” mindset, including between  
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44 263 tertiary centres and smaller services, and even siloed approaches within tertiary centres.  
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48 264 The wordiness of guidelines was frequently criticised. Poor accessibility exacerbated dissatisfaction.  
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50 265 Participants using guideline websites found navigation difficult. The majority felt current guidelines  
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52 266 needed to be reviewed, updated, or in some views, developed. Some called for more prescriptive  
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54 267 guidelines “to rule out grey areas”.  
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“Guidelines – they are not easy to find; website is not intuitive, guidelines are under  
“metabolic” (section). At 3am in the morning, when everyone is tired, (guidelines are) hard  
to find. On-line - so many guidelines. Use most recent but many are out of date.”  
(Paediatrician\_A)

## Discussion

In looking at the experiences of Australian health professionals with neonatal jaundice management, challenges with implementing evidence-based care have been revealed. Several gaps in effective implementation were identified alongside feelings of inability to enact effective change. These issues are likely to apply beyond neonatal jaundice management to the wider use of evidence-based care.

Four of five contexts relevant to clinical practice guideline implementation identified in the meta-review exploring barriers and facilitators,(16) were evident in this study: the clinical guidelines themselves, the health system, the socio-political context and health professionals. This study also identified particular challenges for evidence-based care when adverse events are rare.

Consistent with the most frequently mentioned barrier to guideline implementation in the meta-review(16) were clinical guidelines themselves, particularly with lack of clarity. Other issues such as problems with credibility and day-to-day practice feasibility were also present and appear to be related to inconsistency, lack of standardisation, and unnecessary wordiness. Poor accessibility to guidelines exacerbated dissatisfaction and fuelled scepticism about guideline usefulness.

Barriers identified in the health system context in the meta-review, lack of time, resources, and specialised personnel(16) were also raised in this study. Two other health system developments were linked to possible unintended consequences for neonatal jaundice management. Early discharge practices were directly attributed to creating difficulties for timely diagnosis. Participants pointed out that in the context of early discharge greater need for parent awareness of neonatal jaundice exists. Predictors of discharge ‘readiness’ explored in a US study involving 185 mothers,

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3 292 suggest that potential problems could be ameliorated by good pre-discharge education practices,  
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5 293 although education depends on what, and how, nurses are able to teach mothers before leaving  
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7 294 hospital.(32) Workforce casualisation was another health system issue identified as a potential  
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10 295 barrier to good care for midwives in particular, reducing opportunities to acquire and reinforce  
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12 296 neonatal jaundice knowledge.  
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15 297 The political and social context identified in the meta-review included barriers such as absent or  
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17 298 poor leadership, teamwork difficulties; and lack of agreement between colleagues around guideline  
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19 299 implementation.(16) In this study, issues of leadership and implementation agreement were also  
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21 300 raised although interprofessional conflict was more frequently reported. Problems with  
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23 301 interprofessional boundaries in health care can be found across the literature. For example,  
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25 302 professional boundaries have impeded attempts to deliver best practice in unintended or  
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27 303 unexpected ways. In Wales, an attempt to reduce unnecessary childbirth interventions by promoting  
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29 304 midwife-led care using a clinical pathway found stricter boundary delineation actually reduced the  
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31 305 scope of midwifery practice.(33) Whereas in Australia, inter-professional differences affected  
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33 306 communication and information transfer in a study looking at child and family health services.(34)  
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35 307 Problems with interprofessional boundaries and communication have consistently been highlighted  
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37 308 in investigations into patient harm in maternity and neonatal services in England. (35-38)  
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43 309 Key to resolving professional conflicts is understanding that divergent perceptions do arise between  
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45 310 disciplines, and even within the same discipline. This was evident in this study where the inclusion of  
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47 311 several discipline groups found conflicting paradigms guiding care. This is not unique to Australia or  
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49 312 to neonatal jaundice management. In a large Swedish university hospital study, existing power  
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51 313 relations impeded effective professional teamwork.(39) Awareness of the interrelationships  
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53 314 between professions, particularly when professional knowledge and work overlap, needs  
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55 315 consideration in planning care and in developing guidelines. Interprofessional relationship issues,  
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57 316 characterised by competition and conflict, seem central to professional identity.(40) They need  
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ongoing attention. Interdependent professions can experience constant conflict when continuous engagement related to expert labour and jurisdictional disputes exist. Resolution, when it does occur, tends to be temporary and followed by renewed disturbances.(40) Interprofessional collaboration and the need for synergizing professional roles has been the concern of numerous studies. (41-42) Contextual factors and the autonomous and collaborative aspects of professional roles need to be considered.

Gaps in neonatal jaundice knowledge were acknowledged in this study and in other studies and other countries. For example, in the USA, a cross-sectional study of paediatricians(43) found significant uncertainty in relation to identifying risk factors and using diagnostic approaches to manage neonatal jaundice. Congruent findings were also found in a root-cause analysis of 125 full-term infants with acute bilirubin encephalopathy voluntarily reported to the Pilot USA Kernicterus Registry (1992 to 2004), where the progression to hazardous bilirubin levels was attributed to the inability of multiple health professionals across multiple sites to identify at-risk infants or to manage severe hyperbilirubinemia in a timely way.(44)

An important finding of this study, unrelated to previous studies in this area, relates to particular challenges when adverse events are rare. Low case frequency may give clinicians false confidence that processes are working. The incidence of severe neonatal outcomes arising from extreme neonatal hyperbilirubinemia in Australia, when reported by clinicians, is around 10 per 100 000 live births.(6) While international comparisons are difficult due to definitional differences, including serum cut-off levels, gestational age ranges, and methods of data collection, a Swedish study that identified cases of kernicterus (bilirubin encephalopathy) through medical records, found almost half were most likely avoidable. These were attributed to failure to adhere to best practice, including untimely or no bilirubin screening, misinterpretation of bilirubin levels, and delayed or failure to initiate treatment.(45) That some health professionals in this study dismissed the possibility of severe adverse outcomes in Australia is concerning, particularly as lack of awareness of the

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possibility of poor outcomes can be the most significant barrier to improving patient safety.(46) The absence of ongoing reporting of all adverse neonatal outcomes, including severe neonatal jaundice, appears to be critical. In the absence of adverse outcome data, there is little opportunity for health professionals to build knowledge or to make reasonable cost-benefit judgements.

**Strengths and Limitations**

Both strengths and limitations are present. Several health disciplines across geographical and work settings in Australia were involved, providing a broad range of perspectives. Limitations include the extended period for data collection and analysis, which were driven by practical constraints. The study was conducted over a staggered period, somewhat mirroring the process of guideline development. While not ideal, delay was unavoidable and allowed opportunity to confirm that little change in neonatal jaundice management and clinical guidelines had occurred.(17) The slow pace of analysis also gave time for reflection. The insider-outsider status of the primary researcher offered potential to interpret data in different ways, making reflexivity critical and the field journal invaluable. The decision not to record interviews may be viewed by some as a limitation but also encouraged participation and all scripts were verified by interviewees. Interview scripts written directly after interviews have been shown to have similar quality to audio-recorded transcripts.(27) Despite its limitations, this paper presents the most contemporary views of health professionals on how neonatal jaundice is managed in Australia.(47)

**Conclusion**

Multiple barriers to the provision of evidence-based care related to neonatal jaundice management are experienced by health care professionals in Australia. Clinical guidelines are not sufficient to support health professionals deliver evidence-based care in the complex contexts in which they work. Implementation strategies for evidence-based practice need to take account of health professionals’ experiences and the challenges they face. Implementation strategies for neonatal jaundice management need to consider how to raise awareness of the importance of avoiding

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severe adverse outcomes, despite their rarity, the consequences are devastating. Addressing issues that lead to disjointed care or poor knowledge of neonatal jaundice is essential. Gaps in evidence-based practice arise even when clinical guidelines exist, and health professionals do not know how to address them.

#### **Contributor statement**

C.T. conceived the study design and collected all data. C.T. wrote the main manuscript text with support from D.H. All authors reviewed the manuscript.

#### **Competing interests**

The authors declare that they have no conflict of interest.

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**Figure 1-** Analysis of 41 interviews with health professionals: two major themes and explanatory sub-themes.

**Data Availability Statements**

All data relevant to the study is included within article or uploaded as supplementary information.

De-identified interview scripts are available upon reasonable request from a controlled access repository. Deidentified interview scripts are available upon reasonable request from a controlled access repository (Figshare: <https://figshare.com/s/8cd109d0a2b49ac8071c>). Reuse is permitted when there is a published protocol or detailed plan for analysis.

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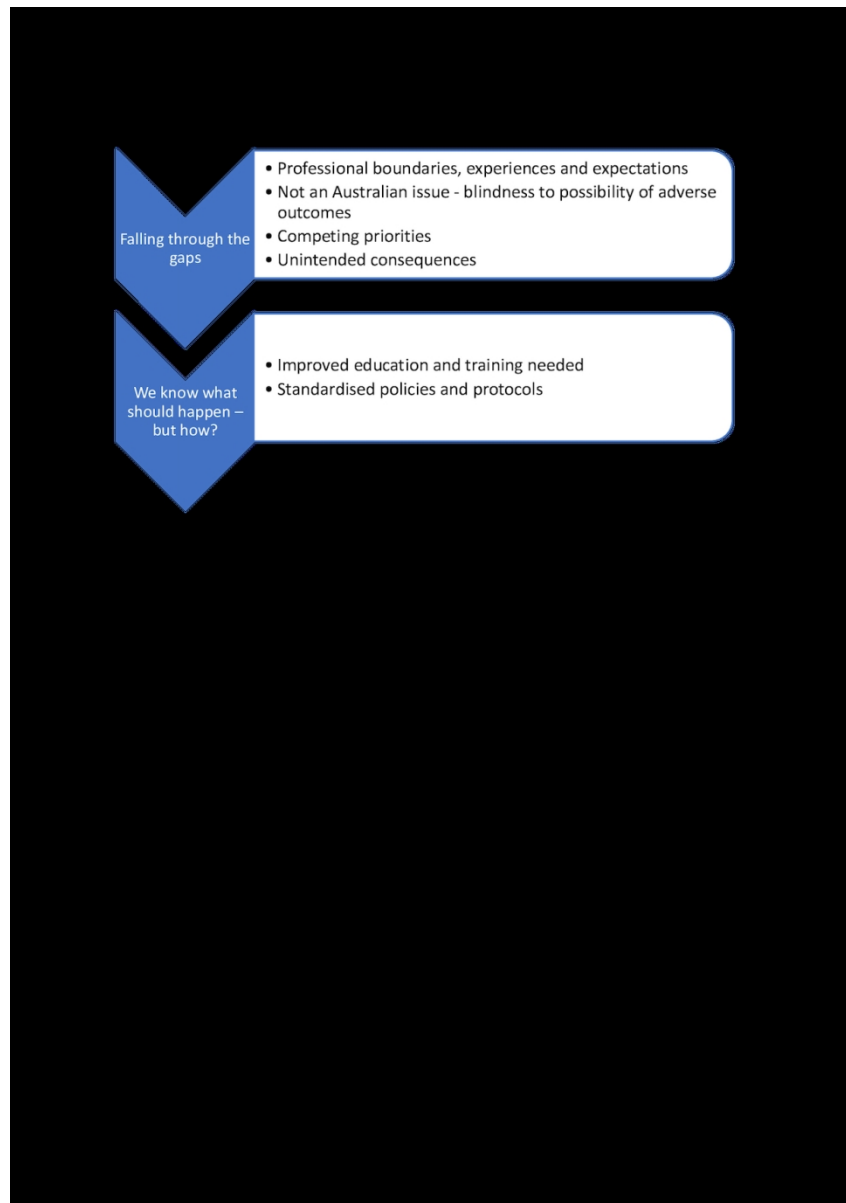


Figure 1 Themes and sub-themes: Analysis of 41 interviews

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## Supplementary File: Interview/Discussion Guide

### Theme List

- a) general experience
- b) how neonatal jaundice is managed
- c) educational preparation
- d) policy and guidelines
- e) research and ongoing professional development, and
- f) identified gaps.

### Prompts

Questions were modified depending on relevance to the participant health professional category.

1. How long have you working as a (type will be specified)? Can you tell me a bit about yourself and what your work involves?
2. What has your general experience been in relation to neonatal jaundice – its recognition, assessment and management?
3. Do you think neonatal jaundice is well managed?
4. Does your organisation have a surveillance strategy for neonatal jaundice?
5. Approximately how many cases of newborn jaundice have you observed? Approximately how many of these required testing?
6. How is jaundice assessed? Can you outline the steps?
7. To what extent have you relied on visual estimation of jaundice?
8. When is a bilirubin test ordered?
9. How is bilirubin tested where you work? What technologies and processes are involved?
10. How do you interpret bilirubin levels? Above what level is treatment considered?
11. What is the highest level of bilirubin you have observed?
12. Have there ever been problems with the testing equipment? If so, can you recall what these problems entailed?
13. Are you aware of any jaundice management guidelines? What do you think about these guidelines? Do you use them? How are these guidelines developed and reviewed?
14. What training is provided to you, and by whom, in relation to neonatal jaundice?

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15. Are you happy with the level of training and ongoing professional development offered to you in relation to neonatal jaundice?
16. How do you keep up to date in terms of the local, national and international literature relating to the management of neonatal jaundice?
17. Do you have any idea of the percentage of neonates readmitted for treatment of jaundice?
18. How confident are you about the risk factors for severe neonatal jaundice? Can you tell me what they are?
19. Do you know what the potential outcomes are if neonatal jaundice is unmonitored or untreated?
20. Over the last ten years or so, how have you adjusted your practices in relation to the management of neonatal jaundice? Consider technology advancements, early discharge policies, etc.
21. From your experience, are there any obstacles in the effective management of neonatal jaundice?

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<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

### Title and abstract

<b>Title</b>	Experiences with neonatal jaundice management in hospitals and the community: Interviews with Australian health professionals.
<b>Abstract</b>	Summary of key elements using required abstract format

### Introduction

<b>Problem formulation</b>	Page 4/Lines 2-21
<b>Purpose or research question</b>	Page 4/Lines 21-27

### Methods

<b>Qualitative approach and research paradigm</b>	Page 5/Lines 29-65
<b>Researcher characteristics and reflexivity</b>	Page 6/Lines 66-71.
<b>Context</b>	Page 4/ Lines 2-25 Page 5/ Lines 26-49 Page 6/ Lines 62-65 Page 7/ Lines 75-78
<b>Sampling strategy</b>	Page 5/ Line 35
<b>Ethical issues pertaining to human subjects -</b>	Page 7/ Lines 72-74
<b>Data collection methods</b>	Page 5/Lines 29-49 Page 6/Lines 50-59
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### Results/findings

<b>Synthesis and interpretation</b>	Page 8/ Line 96 and Figure 1
<b>Links to empirical data</b>	Pages 8-18 – cited throughout

### Discussion

<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b>	Pages 15-18/Lines 275-345
<b>Limitations</b>	Page 18/Lines 348-352

### Other

<b>Conflicts of interest</b>	Page 19 - No conflict of interest declared by authors - Line 374-375
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Funding	Page 19 -No external funding – Line 376-377
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