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## 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.

## 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.
- 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

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## 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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1	Background
2	Worldwide, neonatal jaundice accounts for considerable morbidity and mortality.(1-4) In 2016,
3	neonatal jaundice accounted for over 1300 deaths per 100,000 livebirths and was ranked seventh
4	among all causes of death in the early-neonatal period.(2-4) Severe adverse outcomes associated
5	with neonatal jaundice are uncommon in high-income countries, but do occur and may be
6	preventable, creating an ongoing challenge for health care standards.(4, 5) In Australia, the findings
7	from a surveillance study conducted between 2010 and 2013 to determine the incidence of extreme
8	hyperbilirubinemia (9.4 per 100,000 livebirths) and bilirubin encephalopathy (0.6 per 100 000
9	livebirths) in term and near-term neonates,(6) showed that at least 20 to 25 babies are affected
10	every year. Extreme neonatal hyperbilirubinaemia can result in long-term neurological dysfunction,
11	including brain damage and even death.(4-10)
12	Deficiencies in the care of jaundiced newborns have been identified as contributing to adverse
12	outcomes.(11-14) Care deficiencies need to be minimised, particularly when adverse consequences
13	have enormous personal costs as well as lifelong health and social costs.(14, 15) Modern health care,
15	built on evidence-based practice, commonly relies on clinical guidelines. However, implementation
16	of clinical guidelines can be difficult. A meta-review of 25 systematic reviews exploring the barriers
17	and facilitators to guideline implementation(16) identified five contexts showing its complexity: the
18	clinical guidelines themselves; the health system; the socio-political context; health professionals;
19	and patients.
17	
20	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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## 25 Methods

1 2

> 26 A gualitative descriptive design to explore health professionals' experiences and perspectives(21, 22) 27 used semi-structured interviews and an interpretivist approach(23) to gain understanding of the 28 experiences of health professionals across Australia with the care of jaundiced newborns. A 29 purposive maximum variation sampling process was adopted. (24) Potential participants were 30 approached in writing either directly, for those in private practice, or indirectly via institutional 31 leaders for those working in maternity hospitals, universities, and government departments. 32 Recruitment progressed to ensure a mix of disciplines, geographical areas and settings and 33 continued until data saturation was achieved and no new themes emerged. Data were collected 34 over two years, between August 2011 and December 2013. Interview topics included personal 35 preparation and experiences of neonatal jaundice; knowledge of jaundice-related neonatal 36 morbidity, associated policies and guidelines; and thoughts about any practice adjustments needed 37 for better neonatal jaundice management. Interviews were conducted either face-to-face or by 38 telephone and ranged from 20 to 120 minutes in duration (average 65 minutes). Interviews were not 39 audio-recorded. Detailed notes were taken, including verbatim comments. Interview scripts were 40 completed after each interview to minimise recall bias(25) and returned to participants for 41 verification. This approach aimed to facilitate participation by recognising sensitivities with audio 42 recordings about clinical care. A field journal was maintained to assist in validation and 43 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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2 3 4	50	within and between cases to ensure integrity of the theme boundaries. Coding was checked several
5 6	51	times, including independent confirmation by two experienced researchers who read the first five
7 8	52	interviews and by a third researcher who compared final codes against a data sample. Illustrative
9 10 11 12	53	quotes were identified by discipline.
13 14	54	Reflexivity was critical as the first author intersected with the data in several ways. The study was
15 16	55	part of doctoral studies motivated by personal experience as a mother of a child diagnosed with
17 18 19	56	kernicterus and also as a nurse and policy and program advisor. Ezzy (2002) observed that personal
20 21	57	experience typically shapes the definition of a research problem(28) and how data are collected and
22 23	58	analysed; and so is also a data source about the research problem (2002: 153). A mindset of
24 25 26	59	'conscious partiality'(1999: 20)(29) was cultivated.
27 28 29	60	Ethics approval was given by the university Ethics Committee (FHEC11/47), and by respective health
30 31	61	and medical research committees throughout Australia. Participation was voluntary and informed
32 33 34	62	consent was required prior to all interviews. No one withdrew.
35 36 37	63	Patient and public involvement
38 39	64	The approach taken for this research was to focus on practice aspects of evidence-based care rather
40 41 42	65	than look at the impact of current practice on infants and families. Study participants were all health
42 43 44	66	professionals who provided informed consent. Plans for dissemination of results were relayed to all
45 46	67	participants and included publication in a journal and presentation in various fora.
47 48 49	68	Results
50 51 52	69	Participants
52 53 54	70	Forty-one health professionals from six broad discipline areas were interviewed (nursing [3],
55 56	71	midwifery [15], medicine [12], pathology [2], clinical education [6], and policy development [8]). The
57 58	72	12 doctors came from four different specialty areas (general practice/obstetrics, paediatrics and
59 60	73	neonatology). The majority (66%) had 10 or more years professional experience. Five participants

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3 4	74	worked across state boundaries (12%). Seven participants working in policy development also had
5 6 7	75	clinical roles.
8 9 10	76	Findings
11 12 13	77	Two major themes and explanatory sub-themes were found (see Figure 1).
14 15 16	78	Falling through the gaps
10 17 18	79	This theme reflected views and reported experiences that some neonates were "slipping through
19 20	80	the net" as a consequence of their neonatal jaundice management. Four explanatory sub-themes
21 22	81	were associated with this theme: professional boundaries; blindness to possibility of adverse
23 24 25	82	outcomes; competing professional development priorities; and unintended consequences.
26 27	83	Professional boundaries
28 29	84	Gaps arising from issues related to professional boundaries were revealed across different
30 31	85	professional groups and included limitations in knowledge and experience. Relationships and
32 33 34	86	communication appeared to be affected. Knowledge gaps and lack of experience meant adverse
35 36	87	outcomes were possible. For example, several doctors linked lack of knowledge in junior doctors as a
37 38	88	risk, for example:
39 40	89	"Trying to get exposure to cover all aspects of neonatal care has been an ongoing issue.
41 42 43	90	Learning about neonatal jaundice is not in any formal way mandated in training of general
44 45	91	paediatricians." (neonatologist_C)
46 47	92	
48 49	93	Midwives, including educators and those involved in policy development, also linked lack of
50 51 52	94	adequate knowledge and clinical experience to poorer outcomes. One midwife summed up the
53 54	95	situation this way:
55 56	96	" [Neonatal jaundice] is probably not managed that well there is the potential for it to
57 58	97	get missedthere is no surveillance strategy there is a deficit in the learning junior
59 60	98	doctors lack experience; they are not good at putting the picture together; they may not

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2 3 4	99	even have seen the babymidwives are generally not able to sign pathology slipsIf the
5 6	100	baby is starting to get jaundice within 24 hours – will call the paediatrician to look at the
7 8	101	baby; we monitor – see how it goesmake sure feeding is happening frequentlyIf early
9 10 11	102	discharge –will home visitIt might not be until the home visit that the midwife sees that
12 13	103	the baby is bright yellowParents may think the baby has olive skin. Parents are not
14 15	104	trained to look and assess Guidelines and protocols are only looked at when an issue
16 17 19	105	comes up." (Midwife_C)
18 19 20	106	Professional boundaries rising from poor relationships and poor communication created potential
21 22	107	gaps in care, particularly when role conflict existed. The most common example was differences
23 24	108	between medical and midwifery paradigms, sometimes described as interventionist and non-
25 26 27	109	interventionist approaches. The impact was evident in descriptions of assessment approaches.
27 28 29	110	Midwives referred to using "intuition" or "instinct" as part of their professional assessment. In
30 31	111	contrast, medical practitioners were likely to report erring on the side of caution for both testing and
32 33	112	treating, "just in case". As one said:
34 35 36	113	"we have to do that for fear of kernicterus. At a serum bilirubin level of 310, the baby
37 38	114	receives treatment. It is not necessarily the right thing to do but don't want to miss
39 40 41	115	pathological jaundice." (Paediatrician_C)
42 43		
44 45	116	Tension between different professional relationships was evident in several interviews, such as
46 47	117	between pathology personnel and clinical staff:
48 49 50	118	"There have been specific problems measuring bilirubin for a long time; trying to get it
51 52	119	right; there is a combination of things; measurement, early discharge, lack of knowledge, lab
53 54	120	measuring delay, haemolysed samples. Lab error is unlikely; if there is a mistake it is
55 56 57	121	repeated." (Pathologist_C)
57 58 59		
60		

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2 3 4	122	Professional boundaries affecting care were also reported within speciality groups in the same
5 6	123	discipline, for example:
7 8	124	"There are conflicting views between the medical consultant and the paediatrician for
9 10 11	125	example in a baby with high SBR [serum bilirubin] the medical consultant will say put the
12 13	126	baby under two lights; the paediatrician will visit later and say 'no just use one light'."
14 15	127	(Midwife_A)
16 17	128	Professional boundaries affecting communication were most evident in accounts of absent feedback
18 19	129	when neonatal jaundice was suspected, affecting confidence among less experienced professionals
20 21 22	130	when potential cases were suspected.
22		
24 25	131	"if you are seeing newborns babies all time, your skills are better, your assessment skills
26 27	132	are better, when compared to midwives who only occasionally work with babies; you have a
28 29	133	different perspective. There is a potential for over-reacting and under-reacting. I tend to
30 31 32	134	overreact." (Educator, maternal and child health/midwife_C)
33		
34 35	135	Blindness to possibility of adverse outcomes
	100	
36 37	136	Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in
36 37 38 39		
36 37 38 39 40 41	136	Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in
36 37 38 39 40	136 137	Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in Australia. Two participants were openly cynical about the possibility of kernicterus diagnoses in
36 37 38 39 40 41 42 43 44 45 46	136 137 138	Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in Australia. Two participants were openly cynical about the possibility of kernicterus diagnoses in Australia, including one paediatrician, who despite reporting experience with many jaundiced
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3 4	146	"in passing". Despite several comments about higher proportions of Asian women readmitted with
5 6	147	jaundiced babies, only five participants (two paediatricians, a neonatologist, midwife and neonatal
7 8	148	nursing educator), considered the needs of genetic diversity and ongoing population changes, aware
9 10 11	149	of a clinical trial conducted in one health service.
12 13 14	150	Very few participants recognised the increased risk for First Nation Australians. One paediatrician
15 16	151	who worked in an area with a higher proportion of First Nation residents and those with Asian
17 18 19	152	backgrounds, questioned the association with skin colour, commenting:
20 21	153	"One cannot make assumptions about ethnic heritage; there has been much exchange of
22 23	154	genetic material over the years. Pigmentation is not fully developed in the first few weeks of
24 25	155	life." (Paediatrician_A)
26 27	156	Competing professional development priorities
28 29 30	157	Almost all health professionals acknowledged difficulties in keeping abreast of research evidence;
30 31 32	158	some felt individuals were responsible to keep up-to-date, but most relied on others to make
33 34	159	research information available.
35 36	160	"I don't go looking for [information, literature] " (Midwife_B)
37 38	161	Participants who felt unable to keep up with research, also talked about other priorities, lack of
39 40 41	162	access to resources or the size of the challenge:
42 43	163	"Keeping up to date with research is difficult. A significant number of midwives don't do it
44 45	164	well. If outside the system, it is difficult, if not enrolled in University. How many journals can
46 47	165	you subscribe to? It costs money. You rely on Google. You give up. Access is difficult.
48 49 50	166	Enrolling in University costs money and you need time" (Midwifery educator/consultant_C)
51 52	167	Most participants agreed that neonatal jaundice was one of many conditions that health
53 54	168	professionals need to know about. Several acknowledged lack of understanding of normal
55 56	169	physiology or differences between physiological and pathological jaundice. Overall, professional
57 58 59 60	170	development opportunities on neonatal jaundice care were limited.

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1 2		
- 3 4	171	Unintended consequences
5 6	172	Systemic issues within service delivery and organisations revealed involved unintended
7 8	173	consequences, such as the absence of mechanisms to document adverse effects. Some participants
9 10 11	174	pointed out that without such information measuring impact is difficult. Participants cognisant of
12 13	175	potential consequences remarked:
14 15	176	"One may not know the outcome of severe neonatal jaundice for years. Hearing loss may be
16 17	177	evident within hours." (Pathologist_D&F)
18 19 20	178	"Common reasons for readmission are G6PD, ABO incompatibility, dehydration, bruising.
20 21 22	179	There is less awareness around these. The number of babies readmitted is not coded as
23 24	180	separate. It is not easy to get this information." (Neonatologist_E)
25 26	181	Many interviewees commented on the potential cost of testing, which was commonly considered in
27 28 29	182	terms of over-testing and over-treatment. One participant said:
30 31	183	"You would need to test every parent and child. Test fathers, test cord blood. Per baby it
32 33	184	would be \$150 extra assuming 200,000 babies born per year – there would not be much
34 35	185	benefit." (Paediatrician_C)
36 37 38	186	In contrast, another participant felt it would be cheaper to test every baby "as then the health
39 40	187	service cannot be sued". Several doctors and a pathologist raised the potential costs associated
41 42	188	with one missed case.
43 44	189	Early discharge of mothers and babies was commonly identified as a potential problem for neonatal
45 46 47	190	jaundice identification. All participants working in hospital postnatal wards identified early discharge
47 48 49	191	as a barrier to developing better clinical knowledge:
50 51	192	"There is a concern about early discharge. It is a problem in Australia. It seems greater [than
52 53	193	in other countries]. Our women get kicked out. Monitoring is variable across Australia. What
54 55	194	is the monitoring process?" (Neonatologist_C)
56 57 58	195	Issues arising from early discharge included variability in post-discharge care, where neonatal
58 59 60	196	jaundice management was variously described as "haphazard" or dependent on "competing

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2 3 4	197	demands" with "no dedicated surveillance" measures in place. While one neonatologist described a
5 6	198	robust community system, numerous others, including other neonatologists, did not concur:
7 8	199	"Need better way of streamlining taking serum bilirubin levels at home. Would need to
9 10 11	200	report to the registrar. All midwives at home should perhaps carry a bilirubinometer.
12 13	201	Institutions vary – each hospital will have its own policies Need resources for daily home
14 15	202	visits for a minimum of three days until the maternal and child health nurse kicks in; need
16 17	203	lactation support." (Neonatologist_C)
18 19	204	Contributing to uncertainty about patient care trajectories was growing reliance on a casualised
20 21 22	205	workforce, particularly in midwifery, which was seen to affect skill and knowledge development:
23 24	206	"Midwives, we are reliant on them for recognising and assessing; they are a mixed bunch;
25 26	207	quite a number do shifts in post-natal ward. They are semi-deskilling themselves. Not
27 28	208	keeping up to date. They occasionally take a while to properly communicate regarding
29 30 31	209	jaundiced cases." (Paediatrician_C)
32 33 34	210	Poor knowledge of neonatal jaundice among health professionals also affects communication with
35 36	211	parents about the condition. Some participants pointed out that no specific information for parents
37 38 39	212	existed while others were concerned not to overwhelm parents with more information than needed.
39 40		
41 42	213	We know what should happen – but how?
43 44	214	The second major theme was the perception among participants that while they knew what was
45 46 47	215	required to improve care, they were unsure how to achieve those changes.
48 49	216	Improvements in education and training
50 51	217	Almost all participants expressed needs for better education, particularly for midwives and junior
52 53	218	doctors and parents. Several participants suggested that links between curriculum, guidelines and
54 55	219	clinical practice were missing:
56 57 58	220	"There was a little bit of education around neonatal jaundice during medical training; not
59 60	221	thorough; not much at all. It should be covered better especially for GP obstetricians. My

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1 2		
2 3 4	222	general knowledge is not great about neonatal jaundice. There is a midwife educator
5 6	223	maybe should have a bigger role. This may include keeping in touch with current research
7 8	224	publications; to let us know what is out there." (GP/Obstetrician_C)
9 10 11	225	Guidelines were frequently portrayed as ineffective tools for evidence-based care. The development
12 13	226	and update of clinical guidelines was described as time-consuming. Several participants reported
14 15	227	that guidelines were not included in their professional training and were considered difficult to
16 17	228	navigate and not specific enough to be useful.
18 19	229	"Guidelines. Don't use them, don't look at these." (Midwifery educator_C)
20 21 22	230	"We need concrete guidelines around when to take SBR [serum bilirubin], for example if the
23 24	231	jaundice is below the belly button, you need to do a blood test. Need to take way
25 26	232	subjectivity." (Educator/maternal and child health coordinator/midwife_C)
27 28	233	Standardised policies and protocols
29 30		
31 32	234	Most participants described policies and processes relating to neonatal jaundice management as
33 34	235	variable and viewed as significant barriers to achieving necessary changes. Underpinning concerns
35 36 27	236	were inconsistent or confusing language. Several participants pointed to examples of how different
37 38 39	237	types of jaundice were described and assessed. For example, "clinical jaundice" was used to describe
40 41	238	jaundice requiring a blood test and "jaundice" used when "severe jaundice" meant. Conflation
42 43	239	created confusion—and, in the views of some participants—diminished the importance of severe
44 45	240	bilirubin among clinicians.
46 47		
48 49	241	While calls for consistency in neonatal jaundice management came from across discipline areas, all
50 51	242	conceded that reaching agreement was difficult. Some health professionals felt there was already
52 53	243	multidisciplinary collaboration in policy and guideline development, while others believed such
54 55 56	244	collaboration to be missing. Challenges included a "them-and-us" mindset, including between
57 58 59 60	245	tertiary centres and smaller services, and even siloed approaches within tertiary centres:

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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	246	The wordiness of guidelines was frequently criticised. Poor accessibility exacerbated dissatisfaction.
	247	Participants using guideline websites found navigation difficult. The majority felt current guidelines
	248	needed to be reviewed, updated, or in some views, developed. Some called for more prescriptive
	249	guidelines "to rule out grey areas".
	250	"Guidelines – they are not easy to find; website is not intuitive, guidelines are under
	251	"metabolic" (section). At 3am in the morning, when everyone is tired, (guidelines are) hard
	252	to find. On-line - so many guidelines. Use most recent but many are out of date."
	253	(Paediatrician_A)
23 24	254	Discussion
25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44	255	In looking at the experiences of Australian health professionals with neonatal jaundice management,
	256	challenges with implementing evidence-based care have been revealed. Several gaps in effective
	257	implementation were identified alongside feelings of inability to enact effective change. These issues
	258	are likely to apply beyond neonatal jaundice management to the wider use of evidence-based care.
	259	Four of five contexts relevant to clinical practice guideline implementation identified in the meta-
	260	review exploring barriers and facilitators, (16) were evident in this study: the clinical guidelines
	261	themselves, the health system, the socio-political context and health professionals. This study also
	262	identified particular challenges for evidence-based care when adverse events are rare.
45 46 47	263	Consistent with the most frequently mentioned barrier to guideline implementation in the meta-
48 49	264	review(16) were clinical guidelines themselves, particularly with lack of clarity. Other issues such as
50 51	265	problems with credibility and day-to-day practice feasibility were also present and appear to be
52 53	266	related to inconsistency, lack of standardisation, and unnecessary wordiness. Poor accessibility to
54 55 56 57 58 59	267	guidelines exacerbated dissatisfaction and fuelled scepticism about guideline usefulness.
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> 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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relations impeded effective professional teamwork.(33) Awareness of the interrelationships between professions, particularly when professional knowledge and work overlap, needs consideration in planning care and in developing guidelines. Interprofessional relationship issues, characterised by competition and conflict, seem central to professional identity.(34) They need 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.(34)

00 Gaps in neonatal jaundice knowledge were acknowledged in this study and in other studies and 01 other countries. For example, in the USA, a cross-sectional study of paediatricians(35) found 02 significant uncertainty in relation to identifying risk factors and using diagnostic approaches to 03 manage neonatal jaundice. Congruent findings were also found in a root-cause analysis of 125 full-04 term infants with acute bilirubin encephalopathy voluntarily reported to the Pilot USA Kernicterus 05 Registry (1992 to 2004), where the progression to hazardous bilirubin levels was attributed to the 06 inability of multiple health professionals across multiple sites to identify at-risk infants or to manage 07 severe hyperbilirubinemia in a timely way. (36)

08 An important finding of this study, unrelated to previous studies in this area, relates to particular 09 challenges when adverse events are rare. Low case frequency may give clinicians false confidence 10 that processes are working. The incidence of severe neonatal outcomes arising from extreme 11 neonatal hyperbilirubinemia in Australia, when reported by clinicians, is around 10 per 100 000 live 12 births.(6) While international comparisons are difficult due to definitional differences, including 13 serum cut-off levels, gestational age ranges, and methods of data collection, a Swedish study that 14 identified cases of kernicterus (bilirubin encephalopathy) through medical records, found almost half 15 were most likely avoidable. These were attributed to failure to adhere to best practice, including 16 untimely or no bilirubin screening, misinterpretation of bilirubin levels, and delayed or failure to 17 initiate treatment. (37) That some health professionals in this study dismissed the possibility of

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318 severe adverse outcomes in Australia is concerning, particularly as lack of awareness of the 319 possibility of poor outcomes can be the most significant barrier to improving patient safety.(38) The 320 absence of ongoing reporting of all adverse neonatal outcomes, including severe neonatal jaundice, 321 appears to be critical. In the absence of adverse outcome data, there is little opportunity for health 322 professionals to build knowledge or to make reasonable cost-benefit judgements.

## 323 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

consider how to raise awareness of the importance of avoiding severe adverse outcomes, despite

their rarity, the consequences are devasting. 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.
- The authors declare that they have no conflict of interest.
- No external funding was received for this research.

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

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## Page/line no(s).

## Title and abstract

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

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	Purpose or research question	Page 4/Lines 21-22

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## Other

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

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

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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.

- 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

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## Background

2 Worldwide, neonatal jaundice accounts for considerable morbidity and mortality.(1-4) In 2016, 3 neonatal jaundice accounted for over 1300 deaths per 100,000 livebirths and was ranked seventh 4 among all causes of death in the early-neonatal period.(2-4) Severe adverse outcomes associated 5 with neonatal jaundice are uncommon in high-income countries, but do occur and may be 6 preventable, creating an ongoing challenge for health care standards. (4, 5) In Australia, the findings 7 from a surveillance study conducted between 2010 and 2013 to determine the incidence of extreme 8 hyperbilirubinemia (9.4 per 100,000 livebirths) and bilirubin encephalopathy (0.6 per 100,000 9 livebirths) in term and near-term neonates,(6) showed that at least 20 to 25 babies are affected 10 every year. Extreme neonatal hyperbilirubinaemia can result in long-term neurological dysfunction, 11 including brain damage and even death.(4-10)

12 Deficiencies in the care of jaundiced newborns have been identified as contributing to adverse 13 outcomes.(11-14) Care deficiencies need to be minimised, particularly when adverse consequences 14 have enormous personal costs as well as lifelong health and social costs. (14, 15) Modern health care, 15 built on evidence-based practice, commonly relies on clinical guidelines, that are developed from the 16 best available evidence, even when such evidence is weak. Implementation of clinical guidelines can 17 be difficult. A meta-review of 25 systematic reviews exploring the barriers and facilitators to 18 guideline implementation(16) identified five contexts showing its complexity: the clinical guidelines 19 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.

## 28 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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telephone after participants provided written informed consent 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(27) 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.(28) 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.(29) 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

within and between cases to ensure integrity of the theme boundaries. Coding was checked several
times, including independent confirmation by two experienced researchers who read the first five
interviews and by a third researcher who compared final codes against a data sample. Illustrative
guotes 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. Enseignement Superieur (ABES) . Protected by copyright, including for uses related to text and data mining, Al training, and similar technologies.

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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.

75 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.

81 Results

82 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.

87 The 12 doctors came from four different specialty areas (general practice/obstetrics, paediatrics and 88 neonatology). The nurses were involved in neonatal care, both within the hospital and in the 89 community. The midwives worked in hospital and/or private practice, involving homebirth and/or 90 postnatal care. The clinical education group included maternal and child health, neonatal care, and 91 midwifery care. The majority of participants (66%) had 10 or more years professional experience. 92 Five participants worked across state boundaries (12%). Seven participants working in policy 93 development also had clinical roles. All eight participants in this group were employed by health 94 organisations and were engaged specifically in the development of neonatal jaundice policy.

95 Findings

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2 3 4 5	96	Two major themes and explanatory sub-themes were found: Figure 1.
6 7	97	Falling through the gaps
8 9 10	98	This theme reflected views and reported experiences that some neonates were "slipping through
11 12	99	the net" as a consequence of their neonatal jaundice management. Four explanatory sub-themes
13 14	100	were associated with this theme: professional boundaries; blindness to possibility of adverse
15 16	101	outcomes; competing professional development priorities; and unintended consequences.
17 18 19	102	Professional boundaries
20 21	103	Gaps arising from issues related to professional boundaries were revealed across different
22 23	104	professional groups and included limitations in knowledge and experience. Relationships and
24 25	105	communication appeared to be affected. Knowledge gaps and lack of experience meant adverse
26 27	106	outcomes were possible. For example, several doctors linked lack of knowledge in junior doctors as a
28 29 30	107	risk, for example:
31 32	108	"Trying to get exposure to cover all aspects of neonatal care has been an ongoing issue.
33 34	109	Learning about neonatal jaundice is not in any formal way mandated in training of general
35 36	110	paediatricians." (neonatologist_C)
37 38 39	111	Midwives, including educators and those involved in policy development, also linked lack of
40 41	112	adequate knowledge and clinical experience to poorer outcomes. One midwife summed up the
42 43	113	situation this way:
44 45	114	" [Neonatal jaundice] is probably not managed that well there is the potential for it to
46 47 48	114	get missedthere is no surveillance strategy there is a deficit in the learning junior
48 49 50	115	doctors lack experience; they are not good at putting the picture together; they may not
51 52	117	even have seen the babymidwives are generally not able to sign pathology slipsIf the
53 54	117	
55 56		baby is starting to get jaundice within 24 hours – will call the paediatrician to look at the
57 58 59	119	baby; we monitor – see how it goesmake sure feeding is happening frequentlyIf early
60	120	discharge –will home visitIt might not be until the home visit that the midwife sees that

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2 3 4	121	the baby is bright yellowParents may think the baby has olive skin. Parents are not
5 6	122	trained to look and assess Guidelines and protocols are only looked at when an issue
7 8	123	comes up." (Midwife_C)
9 10 11	124	Professional boundaries rising from poor relationships and poor communication created potential
12 13	125	gaps in care, particularly when role conflict existed. The most common example was differences
14 15	126	between medical and midwifery paradigms, sometimes described as interventionist and non-
16 17	127	interventionist approaches. The impact was evident in descriptions of assessment approaches.
18 19 20	128	Midwives referred to using "intuition" or "instinct" as part of their professional assessment. In
20 21 22	129	contrast, medical practitioners were likely to report erring on the side of caution for both testing and
23 24	130	treating, "just in case". As one said:
25 26	131	"we have to do that for fear of kernicterus. At a serum bilirubin level of 310, the baby
27 28	132	receives treatment. It is not necessarily the right thing to do but don't want to miss
29 30 31	133	pathological jaundice." (Paediatrician_C)
32 33	134	Tension between different professional relationships was evident in several interviews, such as
34 35 36	135	between pathology personnel and clinical staff:
37 38	136	"There have been specific problems measuring bilirubin for a long time; trying to get it
39 40	137	right; there is a combination of things; measurement, early discharge, lack of knowledge, lab
41 42	138	measuring delay, haemolysed samples. Lab error is unlikely; if there is a mistake it is
43 44 45	139	repeated." (Pathologist_C)
46 47	140	Professional boundaries affecting care were also reported within speciality groups in the same
48 49	141	discipline, for example:
50 51	142	"There are conflicting views between the medical consultant and the paediatrician for
52 53 54	143	example in a baby with high SBR [serum bilirubin] the medical consultant will say put the
55 56	144	baby under two lights; the paediatrician will visit later and say 'no just use one light'."
57 58	145	(Midwife_A)
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2 3 4	146	Professional boundaries affecting communication were most evident in accounts of absent feedback
5 6 7 8 9	147	when neonatal jaundice was suspected, affecting confidence among less experienced professionals
	148	when potential cases were suspected.
10 11 12	149	"if you are seeing newborns babies all time, your skills are better, your assessment skills
13 14	150	are better, when compared to midwives who only occasionally work with babies; you have a
15 16	151	different perspective. There is a potential for over-reacting and under-reacting. I tend to
17 18 19 20	152	overreact." (Educator, maternal and child health/midwife_C)
20 21 22	153	Blindness to possibility of adverse outcomes
23 24	154	Several interviewees could not believe that adverse outcomes from neonatal jaundice occurred in
25 26 27 28 29 30 31 32 33 34 35 36 37 38 39	155	Australia. Two participants were openly cynical about the possibility of kernicterus diagnoses in
	156	Australia, including one paediatrician, who despite reporting experience with many jaundiced
	157	infants, had had no direct experience of adverse outcomes, so felt one was unlikely. Similarly, one
	158	midwife explicitly questioned whether a kernicterus diagnosis was possible in Australia. Several
	159	others commented on the rarity of severe neonatal jaundice in Australia, also raising doubts about
	160	whether serious adverse outcomes occur.
40 41	161	Knowledge of adverse outcomes associated with neonatal jaundice was not considered important in
42 43	162	Australian conditions according to some interviewees. When talking about their clinical education,
44 45	163	the term "kernicterus" was recalled by some midwives as a "scary thing" or reportedly mentioned
46 47 48	164	"in passing". Despite several comments about higher proportions of Asian women readmitted with
49 50	165	jaundiced babies, only five participants (two paediatricians, a neonatologist, midwife and neonatal
51 52 53	166	nursing educator), considered the needs of genetic diversity and ongoing population changes.
54 55	167	Very few participants recognised the increased risk for First Nation Australians. One paediatrician
56 57 58	168	who worked in an area with a higher proportion of First Nation residents and those with Asian
59 60	169	backgrounds, questioned the association with skin colour, commenting:

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3 4	170	"One cannot make assumptions about ethnic heritage; there has been much exchange of
5 6	171	genetic material over the years. Pigmentation is not fully developed in the first few weeks of
7 8 9	172	life." (Paediatrician_A)
9 10 11	173	Competing professional development priorities
12 13	174	Almost all health professionals acknowledged difficulties in keeping abreast of research evidence;
14 15	175	some felt individuals were responsible to keep up-to-date, but most relied on others to make
16 17	176	research information available.
18 19 20	177	"I don't go looking for [information, literature] " (Midwife_B)
21 22	178	Participants who felt unable to keep up with research, also talked about other priorities, lack of
23 24	179	access to resources or the size of the challenge:
25 26	180	"Keeping up to date with research is difficult. A significant number of midwives don't do it
27 28 29	181	well. If outside the system, it is difficult, if not enrolled in University. How many journals can
30 31	182	you subscribe to? It costs money. You rely on Google. You give up. Access is difficult.
32 33	183	Enrolling in University costs money and you need time" (Midwifery educator/consultant_C)
34 35	184	Most participants agreed that neonatal jaundice was one of many conditions that health
36 37 38	185	professionals need to know about. Several acknowledged lack of understanding of normal
39 40	186	physiology or differences between physiological and pathological jaundice. Overall, professional
41 42	187	development opportunities on neonatal jaundice care were limited.
43 44	188	Unintended consequences
45 46	189	Systemic issues within service delivery and organisations revealed unintended consequences, such
47 48 49	190	as the absence of mechanisms to document adverse effects. Some participants pointed out that
50 51	191	without such information measuring impact is difficult. Participants cognisant of potential
52 53	192	consequences remarked:
54 55	193	"One may not know the outcome of severe neonatal jaundice for years. Hearing loss may be
56 57 58	194	evident within hours." (Pathologist_D&F)
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3 4	195	"Common reasons for readmission are G6PD, ABO incompatibility, dehydration, bruising.
5 6	196	There is less awareness around these. The number of babies readmitted is not coded as
7 8	197	separate. It is not easy to get this information." (Neonatologist_E)
9 10 11	198	Many interviewees commented on the potential cost of testing, which was commonly considered in
12 13	199	terms of over-testing and over-treatment. One participant considered the prevention of severe
14 15	200	neonatal jaundice attributed to ABO incompatibility and said:
16 17	201	"You would need to test every parent and child. Test fathers, test cord blood. Per baby it
18 19	202	would be \$150 extra assuming 200,000 babies born per year – there would not be much
20 21 22	203	benefit." (Paediatrician_C)
23 24	204	In contrast, another participant felt it would be cheaper to test every baby "as then the health
25 26	205	service cannot be sued". Several doctors and a pathologist raised the potential costs associated
27 28	206	with one missed case.
29 30 31	207	Early discharge of mothers and babies was commonly identified as a potential problem for neonatal
32 33	208	jaundice identification. All participants working in hospital postnatal wards identified early discharge
34 35	209	as a barrier to developing better clinical knowledge:
36 37	210	"There is a concern about early discharge. It is a problem in Australia. It seems greater [than
38 39 40	211	in other countries]. Our women get kicked out. Monitoring is variable across Australia. What
40 41 42	212	is the monitoring process?" (Neonatologist_C)
43 44	213	Issues arising from early discharge included variability in post-discharge care, where neonatal
45 46	214	jaundice management was variously described as "haphazard" or dependent on "competing
47 48	215	demands" with "no dedicated surveillance" measures in place. While one neonatologist described a
49 50 51	216	robust community system, numerous others, including other neonatologists, did not concur:
52 53	217	"Need better way of streamlining taking serum bilirubin levels at home. Would need to
54 55	218	report to the registrar. All midwives at home should perhaps carry a bilirubinometer.
56 57	219	Institutions vary – each hospital will have its own policies Need resources for daily home
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3 4	220	visits for a minimum of three days until the maternal and child health nurse kicks in; need
5 6	221	lactation support." (Neonatologist_C)
7 8	222	Contributing to uncertainty about patient care trajectories was growing reliance on a casualised
9 10 11	223	workforce, particularly in midwifery, which was seen to affect skill and knowledge development:
12 13	224	"Midwives, we are reliant on them for recognising and assessing; they are a mixed bunch;
14 15	225	quite a number do shifts in post-natal ward. They are semi-deskilling themselves. Not
16 17	226	keeping up to date. They occasionally take a while to properly communicate regarding
18 19 20	227	jaundiced cases." (Paediatrician_C)
21 22	228	Poor knowledge of neonatal jaundice among health professionals also affects communication with
23 24 25	229	parents about the condition. Some participants pointed out that no specific information for parents
26 27	230	existed while others were concerned not to overwhelm parents with more information than needed.
28 29		
30 31	231	We know what should happen – but how?
32 33	232	The second major theme was the perception among participants that while they knew what was
34 35	233	required to improve care, they were unsure how to achieve those changes.
36 37 38	234	Improvements in education and training
39 40	235	Almost all participants expressed needs for better education, particularly for midwives and junior
41 42	236	doctors and parents. Several participants suggested that links between curriculum, guidelines and
43 44	237	clinical practice were missing:
45 46 47	238	"There was a little bit of education around neonatal jaundice during medical training; not
48 49	239	thorough; not much at all. It should be covered better especially for GP obstetricians. My
50 51	240	general knowledge is not great about neonatal jaundice. There is a midwife educator
52 53	241	maybe should have a bigger role. This may include keeping in touch with current research
54 55 56	242	publications; to let us know what is out there." (GP/Obstetrician_C)
56 57 58	243	Guidelines were frequently portrayed as ineffective tools for evidence-based care. The development
59 60	244	and update of clinical guidelines was described as time-consuming. Several participants reported

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3 4 5 6 7 8 9	245	that guidelines were not included in their professional training and were considered difficult to
	246	navigate and not specific enough to be useful.
	247	"Guidelines. Don't use them, don't look at these." (Midwifery educator_C)
9 10 11	248	"We need concrete guidelines around when to take SBR [serum bilirubin], for example if the
12 13 14 15 16 17 18 19 20 21 22	249	jaundice is below the belly button, you need to do a blood test. Need to take way
	250	subjectivity." (Educator/maternal and child health coordinator/midwife_C)
	251	Standardised policies and protocols
	252	Most participants described policies and processes relating to neonatal jaundice management as
	253	variable and viewed as significant barriers to achieving necessary changes. Underpinning concerns
23 24 25	254	were inconsistent or confusing language. Several participants pointed to examples of how different
26 27	255	types of jaundice were described and assessed. For example, "clinical jaundice" was used to describe
28 29 30 31 32 33 34 35 36 37 38 39 40 41	256	jaundice requiring a blood test and "jaundice" used when "severe jaundice" meant. Conflation
	257	created confusion—and, in the views of some participants—diminished the importance of severe
	258	bilirubin among clinicians.
	259	While calls for consistency in neonatal jaundice management came from across discipline areas, all
	260	conceded that reaching agreement was difficult. Some health professionals felt there was already
	261	multidisciplinary collaboration in policy and guideline development, while others believed such
42 43 44	262	collaboration to be missing. Challenges included a "them-and-us" mindset, including between
45 46 47	263	tertiary centres and smaller services, and even siloed approaches within tertiary centres.
48 49 50	264	The wordiness of guidelines was frequently criticised. Poor accessibility exacerbated dissatisfaction.
50 51 52	265	Participants using guideline websites found navigation difficult. The majority felt current guidelines
53 54	266	needed to be reviewed, updated, or in some views, developed. Some called for more prescriptive
55 56	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)

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

Discussion

implementation were identified alongside feelings of inability to enact effective change. These issuesare 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 metareview 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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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.(32) 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.

97 The political and social context identified in the meta-review included barriers such as absent or 98 poor leadership, teamwork difficulties; and lack of agreement between colleagues around guideline 99 implementation.(16) In this study, issues of leadership and implementation agreement were also 00 raised although interprofessional conflict was more frequently reported. Problems with 01 interprofessional boundaries in health care can be found across the literature. For example, 02 professional boundaries have impeded attempts to deliver best practice in unintended or 03 unexpected ways. In Wales, an attempt to reduce unnecessary childbirth interventions by promoting 04 midwife-led care using a clinical pathway found stricter boundary delineation actually reduced the 05 scope of midwifery practice.(33) Whereas in Australia, inter-professional differences affected 06 communication and information transfer in a study looking at child and family health services.(34) 07 Problems with interprofessional boundaries and communication have consistently been highlighted 08 in investigations into patient harm in maternity and neonatal services in England. (35-38)

09 Key to resolving professional conflicts is understanding that divergent perceptions do arise between 10 disciplines, and even within the same discipline. This was evident in this study where the inclusion of 11 several discipline groups found conflicting paradigms guiding care. This is not unique to Australia or 12 to neonatal jaundice management. In a large Swedish university hospital study, existing power 13 relations impeded effective professional teamwork.(39) Awareness of the interrelationships 14 between professions, particularly when professional knowledge and work overlap, needs 15 consideration in planning care and in developing guidelines. Interprofessional relationship issues, 16 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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2 3	342	possibility of poor outcomes can be the most significant barrier to improving patient safety.(46) The
4 5 6 7	343	absence of ongoing reporting of all adverse neonatal outcomes, including severe neonatal jaundice,
	344	
8 9	344	appears to be critical. In the absence of adverse outcome data, there is little opportunity for health
10 11 12	345	professionals to build knowledge or to make reasonable cost-benefit judgements.
13 14	346	Strengths and Limitations
15 16	347	Both strengths and limitations are present. Several health disciplines across geographical and work
17 18 19	348	settings in Australia were involved, providing a broad range of perspectives. Limitations include the
20 21	349	extended period for data collection and analysis, which were driven by practical constraints. The
22 23	350	study was conducted over a staggered period, somewhat mirroring the process of guideline
24 25	351	development. While not ideal, delay was unavoidable and allowed opportunity to confirm that little
26 27 28	352	change in neonatal jaundice management and clinical guidelines had occurred.(17) The slow pace of
29 30	353	analysis also gave time for reflection. The insider-outsider status of the primary researcher offered
31 32	354	potential to interpret data in different ways, making reflexivity critical and the field journal
33 34	355	invaluable. The decision not to record interviews may be viewed by some as a limitation but also
35 36 37	356	encouraged participation and all scripts were verified by interviewees. Interview scripts written
37 38 39 40 41	357	directly after interviews have been shown to have similar quality to audio-recorded transcripts.(27)
	358	Despite its limitations, this paper presents the most contemporary views of health professionals on
42 43	359	how neonatal jaundice is managed in Australia.(47)
44 45	360	Conclusion
46 47 48	361	Multiple barriers to the provision of evidence-based care related to neonatal jaundice management
49 50	362	are experienced by health care professionals in Australia. Clinical guidelines are not sufficient to
51 52	363	support health professionals deliver evidence-based care in the complex contexts in which they
53 54	364	work. Implementation strategies for evidence-based practice need to take account of health
55 56 57	365	professionals' experiences and the challenges they face. Implementation strategies for neonatal
57 58 59 60	366	jaundice management need to consider how to raise awareness of the importance of avoiding

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367	severe adverse outcomes, despite their rarity, the consequences are devasting. Addressing issues

- 368 that lead to disjointed care or poor knowledge of neonatal jaundice is essential. Gaps in evidence-
- 369 based practice arise even when clinical guidelines exist, and health professionals do not know how
- 370 to address them.

### Contributor statement

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

### 0 374 Competing interests

375 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 A	vailability Statements
All data	a relevant to the study is included within article or uploaded as supplementary information.
De-ider	ntified interview scripts are available upon reasonable request from a controlled access

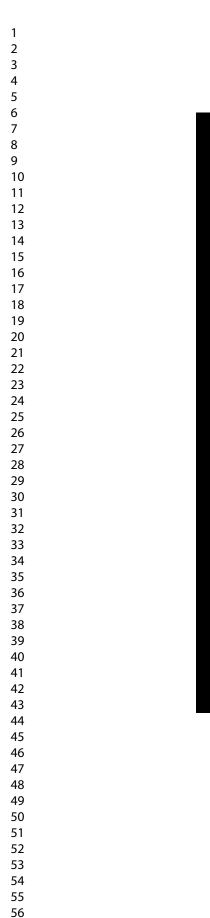
repository. Deidentified interview scripts are available upon reasonable request from a controlled

access repository (Figshare: https://figshare.com/s/8cd109d0a2b49ac8071c). Reuse is permitted

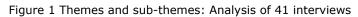
when there is a published protocol or detailed plan for analysis.

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# 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?

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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## Page/line no(s).

#### Title and abstract

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

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	Conflicts of interest	Page 19 - No conflict of interest declared by authors -
		Line 374-375

Page 19-No external funding – Line 376-377		
tor peer teriew only	Funding	Page 19 -No external funding – Line 376-377