

Appendix E –GRADE-CERQual tables

Theme	Illustrative quotes	Methodological limitations	Coherence	Adequacy	Relevance	Confidence
<p>Parent or carer anxiety</p> <p>Parents were concerned about whether they had missed potential warning signs of serious illness in their baby. They also had concerns about not knowing what procedures would be happening in the hospital or understanding what is involved in those procedures</p> <p>Reassurance that they had done the right thing by taking their baby to the hospital helped to reduce anxiety.</p>	<p><i>“Babies can deteriorate so quickly. As a first-time parent you don’t know much, being advised, told what to do is quite important.”</i></p> <p><i>“We were in Emergency and wondering whether we were being overprotective parents and one of the doctors said, ‘you did the right thing’.</i> <i>We were relieved.”</i></p> <p><i>“It was about 40 minutes before we got spoken to or even told well this is what is going to happen. That was the only thing I was a little bit upset about. I never mind waiting. I just wanted to know whether I could wrap him up and put him to sleep or whether he had to be left unwrapped to be assessed and probably for me it was racing through my head and the big thing was</i></p>	<p>Serious¹</p>	<p>Not serious²</p>	<p>Serious³</p>	<p>Serious⁴</p>	<p>Very low</p>

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	<i>fever we have been admitted what is going on what is it they were thinking.”</i>					
<p>Explanation of procedures</p> <p>Parents stated that a clear explanation of what happens in a medical procedure is important, particularly in relation to lumbar punctures.</p> <p>The use of medical terms rather than simple terminology can make it harder to understand either the diagnosis or the tests that are being carried out.</p>	<p><i>“I did not know what they were talking about. They were talking their own language, like jargons, they said it is a UTI and I was like, ‘what is that?’ That’s when I looked on the internet did some research of my own.”</i></p> <p><i>“It’s hard to take all the information in and the wording is important—when they talked about the lumbar puncture that they needed to take the fluid from around the baby’s brain we imagined the needle going into the head, I was standing, I felt my head spin and had to hold on to something.”</i></p>	<p>Serious¹ One study at moderate risk of bias (<i>Limited information about analysis, including triangulation and validation. No acknowledgement of the relationships between researchers and participants</i>)</p>	<p>Not serious²</p>	<p>Serious³</p>	<p>Serious⁴</p>	<p>Very low</p>

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	<p><i>“The doctor that saw us in emergency was brilliant. She drew a diagram of the lumbar puncture, explained what was going to happen, the risks associated with it, I was told what may happen if he didn’t have it so I think I was quite pleased with the information.”</i></p> <p><i>The turning point was when the registrar came in and said they were going to do the lumbar puncture and he sat down and went over everything step by step from the start of the day up until then, what had happened—that was the turning point.”</i></p>					

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	<i>The manner of the doctor in emergency was excellent. He very clearly explained so we knew exactly what was going to happen, that our baby would go through a number of tests, and some would be hard to watch but he was gentle, kind. That in many ways was the key. If you get the explanation first and someone takes the time to sit to tell you what is happening, you are prepared to go through a whole lot of things because you have been warned.</i>					
Decision making and parental or carer involvement Parents valued having a clear explanation of the management plan. Some were either unaware that they had the right to say no to a treatment or didn't feel that this was really an option.	<i>"It was scary because they explained the risks and they said it was up to me but really there was no choice."</i> <i>"The next day I was told you have the right to say no, I didn't know that. You feel a little bit like you are at the mercy of say the nurses or the doctor no one said if you</i>	Serious¹	Not serious²	Serious³	Serious⁴	Very low

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	<p><i>are really uncomfortable with this we can stop.</i></p> <p><i>“When you are sleep deprived, when you are concerned, [and] when you are worried sick and things happen so quick, your head seems to go blank. I was in so much shock I couldn’t come up with any question.”</i></p>					
<p>Format of information</p> <p>Parents indicated that fact sheets would be a helpful way to explain what was happening.</p>	<p><i>“Fact sheets would be really good. It is hard to ask questions when the doctors are rushing in and out. By the time they are back you forget what you were about to ask.”</i></p>	Serious¹	Not serious²	Serious³	Serious⁴	Very low

1. One study at moderate risk of bias (De 2014 - limited information about analysis, including triangulation and validation. No acknowledgement of the relationships between researchers and participants)
2. One study where the themes support the patterns found in the data
3. Results are based on a single study with 36 parents
4. Evidence from a single study. Parents of preterm babies were excluded