

Supplementary Table. Inductive codes, outcome domains and outcome domain categories mapped.

Outcome Domain Categories	Outcome Domains (Outcomes proposed for Delphi)	Inductive code	Descriptive notes on Domain	HiC or LMIC
Neurological Outcomes	Electroencephalogram (EEG) abnormalities	Brain Activity	Parents recalled the importance of measurements relating to brain injury and seizure activity being discussed with them in the NICU. Parents spoke of the significance they placed on neonatal reflexes. They described how healthcare providers looked for responses, tone and changes in reflexes to judge their baby's response to treatment. Being able to swallow or gag was also noted by parents as a welcome sign.  Parents across both HiC and LMICs spoke of their baby's sleeping. For some, sleeping too much was regarded as something associated with illness; others were concerned that their baby was not sleeping enough or had a disturbed sleep pattern. Many of the parents were unsure what was "normal", what they should expect and took their cues from the comments offered by health care providers.	HiC & LMIC
	Neonatal seizures	Seizures		HiC & LMIC
	Brain Injury on imaging	Brain Injury		HiC & LMIC
		Brain Abnormalities		HiC & LMIC
	Severity of encephalopathy	Absent pupillary reflex		LMiC
		Consciousness		HiC & LMIC
		Opening eyes		HiC & LMIC
		Brain Function		HiC
	Absence of Neonatal Reflexes*	Being active/responsive		HiC & LMIC
		Neonatal reflex/reflexes absent (asymmetrical tonic neck reflex, Babinski reflex, grasp reflex Moro reflex, rooting reflex, step reflex, Galant reflex)		HiC & LMIC
	Sleep Disorders*	Sleep difficulties/ Sleeplessness		HiC
Sleepiness/ over sleepiness		HiC & LMIC		

	Normal tone	Tone (ability to support head, neck,)		HiC & LMiC
		Ability to practise “tummy time”		HiC
	Gag reflex (absent)*	Gag reflex (absent)		HiC & LMiC
		Swallow (absent)*		Swallow (absent)
	Need for suctioning (unable to handle secretions)		HiC & LMiC	
Respiratory Outcomes	Ability to breathe normally and unaided*	Breathing ability	Parents spoke of the importance of their child breathing normally, without struggle, and unaided, without the need for breathing machines. They also spoke of the need for their infant to be resuscitated as frightening and made them realise the seriousness of their child’s condition and health.	HiC & LMiC
		Breathing abnormality		LMiC
		Ability to breathe unaided		HiC
		Coughing		LMiC
	Need for neonatal resuscitation*	Need for adrenaline		HiC
		Need for resuscitation		HiC & LMiC
	Oxygen requirement	Continuous positive airway pressure (CPAP) requirement		HiC & LMiC
		High-flow oxygen requirement		HiC
		Oxygen requirement		HiC & LMiC
		Low-flow oxygen requirement		HiC

		Oxygen saturations		HiC
	Need for mechanical ventilation	Mechanical ventilation requirement		HiC & LMIC
		Respirator requirement		HiC & LMIC
		Need for intubation		HiC
		Extubation		HiC & LMIC
		Need for a tracheostomy tube		HiC
Gastrointestinal Outcomes	Feeding intolerance	Vomiting	Parents spoke of their concern for their infant's intolerance to feeding, indicated by vomiting. Independence in feeding was also a worry, and parents discussed whether their infant was able to be fed by their mouth or if they needed to be fed using a tube as a strong concern for their infant's quality of life. The ability of the infant to pass meconium normally and not having blood in the stool was a particular concern of parents in LMICs	HiC & LMIC
	Meconium passage <sup>*</sup>	Ability to pass stool		LMIC
		Ability to digest food		HiC
	Oral feeding ability	Ability to feed		HiC & LMIC
		Feeding difficulties		LMIC
		Ability to eat by mouth		HiC
		Ability to breastfeed		HiC
		Ability to suck		HiC
	Intravenous (i.v.) fluid requirement		HiC & LMIC	

	Need for tube feeding	Need for nasogastric tube feeding		HiC & LMiC
		Need for percutaneous endoscopic gastrostomy (PEG) feeding		HiC
Cardiovascular Outcomes	Abnormal changes in heart rate or rhythm	Heart rhythm/ electrical activity	Parents spoke of the monitors connected to their baby which measured the activity of the heart. They remembered the sounds it made and the doctors and nurses recording information from it. An outcome uniquely identified by HiC parents was the risk of clotting, and the potential need for transfusion described to them by the doctor while their baby was being treated in the NICU.	HiC & LMiC
		Arrhythmia		HiC
		Bradycardia		HiC
	Coagulopathy	Need for platelet transfusion		HiC
Motor Development	<u>General</u> Gross Motor ability	Movement – Absent	Reference was made to their infant's mobility and strength in their legs and arms. For some parents, this went beyond their child's ability to stand unaided or to grasp something in their hand; they also identified outcomes associated with childhood games and with activities they saw as 'normal' for other children. Parents of children who were school-aged recalled the importance of their child's motor development in their ability to undertake sport with other children their age, which was unique to these interviews.	HiC
		Movement (moving fingers, hands, arms, legs, twitching)		HiC
		Ability to crawl		HiC & LMiC
		Ability to walk/ run		HiC & LMiC
		Ability to roll over		HiC & LMiC
		Ability to jump		HiC

		Ability to stand		HiC & LMiC
		Ability to stand independently		HiC
		Ability to bear weight		HiC
		Ability to kneel		HiC
		Ability to sit		HiC & LMiC
		Pulling to standing		HiC
		Ability to reach		HiC
		Weakness in hand/ hands		HiC
		Weakness in arm/arms		HiC
		Weakness in leg/ legs		HiC
		Weakness in body		LMiC
		Reduced mobility in arm/arms		HiC
		Reduced mobility in hand/hands		HiC
		Reduced mobility in foot/ feet		HiC
		Ability to grasp/ pick up objects		HiC & LMiC
		Coordination/ Balance		HiC
		Ability to hold objects		LMiC

	Ability to undertake sport*	Ability to kick a ball		HiC & LMiC
		Ability to undertake sport		HiC
Cognitive Development	General cognitive ability	General cognitive ability	General cognitive ability was a concern for parents of infants of various ages, this included learning difficulties and the need for educational support at school-age.	HiC & LMiC
		Cognitive disability		LMiC
		Learning difficulties		HiC & LMiC
		Need for educational support		HiC
Development (Psychosocial)	Psychological development	Ability to cry	Psychological development was highlighted as important by many parents, including the child's ability to display emotions and connect with others in a meaningful way. Behavioural issues were a concern for parents of HiCs and not LMiCs.	HiC & LMiC
		Smiling		HiC & LMiC
		Happiness		HiC & LMiC
		Laughing		HiC & LMiC
		Being upset		HiC & LMiC
		Being overwhelmed		HiC
		Anxiety (child)		HiC
		Ability to play		HiC &

				LMiC
		Need for Social and Emotional support		HiC
		Social withdraw (child)		HiC
		Peer and family relationships		HiC
	Behavioural issues	Behavioural issues		HiC
Development (Special Senses)	Visual impairment	Visual Impairment	Many parents highlighted the ability to see and hear as something they were concerned about in their child's development. Parents were also concerned for their child having a sensory condition whereby they would become distressed when faced with bright lights loud noises, certain tastes, smells or touch. The child's ability to communicate through speech and sound was also critical for parents.	HiC & LMiC
		Sensory reaction (to light)		HiC & LMiC
		Ability to recognise people/ objects		LMiC
	Hearing Impairment	Hearing impairment		HiC & LMiC
		Reaction to sound/ voices		LMiC
	Heightened sensory sensitivity	Sensitivity to light		HiC & LMiC
		Sensitivity to smell		HiC
		Sensitivity to taste		HiC
	Behaviour in response to a sensory sensitivity	HiC		

Development (Speech & Social)	Ability to make noises/ verbalise*	Ability to make noises	The child's ability to communicate either through speech, noises or gestures was critical to parents.	HiC
		Ability to verbalise		HiC & LMiC
	Speech delay	Speech Delay		HiC & LMiC
		Ability to talk		HiC & LMiC
		Need for Speech and Language Therapy		HiC
	General communication ability	Need to learn sign language		HiC
		Ability to communicate needs		HiC & LMiC
Other Organ Outcomes	Renal Dysfunction	Pass urine	Renal dysfunction was discussed by parents in HiCs only. Contrastingly, hypoglycaemia was only highlighted as important by parents in LMiCs.	HiC
	Hypoglycaemia	Hypoglycaemia		LMiC
Survival/ Living Outcomes	Growth	Weight	Outcomes such as growth, survival, and full recovery from acute illness were described by parents as clear and important indications of how well their child responded to treatment. Survival was considered one of the most important outcomes. Several parents spoke of their infant's passing, and other parents spoke of this as a constant concern they had for their	HiC & LMiC
		Growth		HiC & LMiC
	Survival	Death		HiC & LMiC
		Brain death		LMiC



	Suffering*	Suffering	child when receiving treatment in the Neonatal Intensive Care Unit (NICU). Parents spoke of the suffering of their infant while receiving treatment in the NICU and how they viewed it as important to consider. Speaking of their infant being distressed and suffering in the NICU was difficult for parents to discuss, highlighting the importance of this outcome as an indication to parents of their child's health	HiC
		Pain		HiC
	Full recovery from acute illness	Time to clinical improvement		LMiC
		Recovery/ Reaction to treatment (being stable, consciousness)		HiC & LMiC
		Reduction in dose of medication		HiC
		Discontinuation of treatment		HiC & LMiC
		Symptom-free/ illness-free survival		HiC & LMiC
		Normality after discharge		HiC & LMiC
Patient-reported outcome	Quality of life	Quality of life	Overall quality of life of their child was also considered critical for parents in showing if the treatment their baby received had worked or not.	HiC & LMiC
Long-term Disability	Cerebral Palsy	Cerebral Palsy	Both the diagnosis of epilepsy in the child and the need for ongoing occupational therapy were considered important indicators of improvement following treatment. The diagnosis of cerebral palsy was a concern raised by parents in HiCs alone.	HiC
	Epilepsy	Epilepsy		HiC & LMiC
	Need for Occupational Therapy*	Need for Occupational Therapy		HiC & LMiC
Hospitalisation	Duration of neonatal stay	Admission to the Neonatal Intensive Care Unit (NICU)/	The length their baby was in the NICU being treated and the requirement to re-visit	HiC & LMiC

		Newborn Unit (NBU)	the hospital later in their child's life gave parents an indication of their child's health following treatment.	LMiC
		Duration of hospitalisation		HiC
		Discharge from hospital		HiC
	Re-admission in childhood	Follow-up care/appointments		HiC & LMiC
		Re-hospitalisation		LMiC
Parent-reported outcomes	Parental Involvement in care*	Ability to hold baby	This domain identified a number of outcomes relating to the parent(s) of the infant receiving treatment and how they should be considered in the overall care of their child.	HiC & LMiC
		Ability to touch baby		HiC & LMiC
		Ability to dress baby		HiC
		Ability to bathe baby		HiC
		Ability for parents to change baby's nappy		HiC
		Ability to provide care for baby		LMiC
		Support from HCPs on how to care for the baby		HiC
	Parental attachment with their baby*	Separation from baby (while in the Neonatal Intensive Care Unit)		HiC & LMiC
	Parental sense of loss of normal*	Sense of loss		HiC

	Uncertainty for future wellbeing*	Uncertainty for future wellbeing		HiC & LMiC
	Parental psychological impact of Neonatal Intensive Care Unit (NICU) experience*	Parental Psychological Impact of Neonatal Intensive Care Unit experience		HiC & LMiC
		Sleep deprivation		HiC
		Parent's feeling of being a burden/ out of place in Neonatal Intensive Care Unit		HiC
	Emotional impact on parents	<ul style="list-style-type: none"> <li>• Trauma</li> <li>• Depression</li> <li>• Anxiety</li> <li>• Devastation</li> <li>• Worry</li> <li>• Grief</li> <li>• Guilt</li> </ul>		HiC & LMiC
	Impact of child's condition on parents' relationship*	Impact on parents' relationship		HiC
	Financial burden of health care costs of care for infant on parents*	Impact on parents' ability to work		LMiC
	Parental ability to work*	Impact on parents' ability to work		LMiC
	Impact of child's condition and Neonatal Intensive Care Unit experience on wider family	Impact on wider family (stress, disappointment, sadness, grief etc.)		LMiC

(stress, disappointment, sadness, grief etc.)*	Support from family/ friends	Parents described their experience of communicating with healthcare providers when their baby was receiving treatment in the NICU. Some parents had positive experiences and other parents wished their experience had been better. Parents discussed the importance of being told different information and at different times during their child's treatment. Parents also described how communication could have been improved.	HiC & LMiC
	Having visitors in the hospital		HiC
Having family members (extended) hold the baby	HiC		
Effective communication between parents and HCPs*	Communication regarding diagnosis of infant		HiC & LMiC
	Communication regarding treatment (options)/ explanation of treatment		HiC & LMiC
	Communication regarding need for treatment		HiC
	Communication regarding tests being carried out while the baby was in the Neonatal Intensive Care Unit		HiC & LMiC
	Communication regarding cause of diagnosis		HiC & LMiC
	Communication regarding follow-up care		HiC & LMiC
	Communication regarding progress of the baby		HiC & LMiC
	General communication with	HiC	

		parents (overuse of jargon)		
		Communication regarding the prognosis of the baby (expected outcome/ future)		HiC & LMiC
		Communication regarding how to care for the infant (tube feeding, special needs, seizure identification etc.)		HiC & LMiC
		Communication and positive support for parents		LMiC
		Need for counselling and communication		LMiC
Adverse Events	Adverse events	Skin Rashes	Side effects related to treatment were a concern of parents in LMiCs alone.	LMiC
		Fever		LMiC
		Blood in stool		LMiC

\*Indicates outcomes that were identified by parents but were not identified in our ongoing systematic review of randomised trials and systematic reviews of randomised trials of interventions for the treatment of neonatal encephalopathy.

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