

September 20th, 2023 09:00 - 11:00

## PARALLEL SESSION 6 - EFCNI 1

**ID 923. Modified Delphi Consensus identifying UK neonatal transport research priorities. A comparison of healthcare professionals and parent perspectives in priority setting.**

**Dr Aarti Mistry**<sup>1</sup>, Dr Shalini Ojha<sup>1</sup>, Professor Donald Sharkey<sup>1</sup>

<sup>1</sup>Centre of Perinatal Research, School of Medicine, University of Nottingham, Nottingham, United Kingdom

### Background/Aim

Over the last decade we have observed significant advances in care provision within neonatal transport in the UK. Due to lack of high impact neonatal transport specific research studies, updates in clinical practice have been informed by neonatal/scientific based research, leaving many unanswered questions raised by neonatal transport service providers and users.

Our study aims to identify the top ten UK neonatal transport research priorities most important to healthcare professionals and parents and observes differing perspectives between these cohorts. This abstract presents Phase 2 survey results.

### Method

Using key principles outlined by the James Lind Alliance priority setting guidance, a three phased modified Delphi consensus was formulated and conducted over a 2–year period. The Phase 1 and 2 surveys were sequentially disseminated to healthcare professionals and parents. Each respondent was asked to rank each priority against a 5–point Likert scale. Consensus was defined where >75% of respondents had given

score  $\geq 4$ , those meeting consensus were discussed in the final Delphi priority setting virtual workshop.

## Results

Total of 269 survey responses were analysed from healthcare professionals (n=161) and parents (n=115) over two sequential surveys. Phase 1 survey (n=115 responses): 23/43 research priorities met consensus; 6 new priorities were added after screening of free text responses. Phase 2 survey (n=154 responses), 22/29 research priorities met consensus, differences between parent and healthcare professional scoring shown in (Table). Research priorities encompassing areas of transport risk, thermoregulation and pain and sedation during transport scored highly by both cohorts. Marked differences were observed around priorities exploring transport environment exposures, these were scored highly by healthcare professionals compared to parents. Priorities focusing on infant outcomes showed parents held respiratory outcomes to be of greater importance compared to healthcare professionals whose focus was towards long-term neurological outcomes.

## Conclusion

Differing perspectives observed during priority setting are often reflective of an individual's experience. Engagement of parent perspectives, alongside healthcare professionals has played an invaluable role within this priority setting project; generating holistic neonatal transport research priorities most relevant to today's service providers and their users' needs This evidently will yield greater impact, through targeted funding and research resources.

Phase 2 Research priorities meeting consensus (n=22)	Parent scores (n=55)		Healthcare professional scores (n=99)	
	Score $\geq 4$ (%)	Mean $\pm$ SD	Score $\geq 4$ (%)	Mean $\pm$ SD
1. Preventing harm with equipment failure in neonatal transport	100	4.80 $\pm$ 0.40	89.9	4.53 $\pm$ 0.80
2. Investigating the risk of neonatal transport	90.9	4.49 $\pm$ 0.72	91.9	4.33 $\pm$ 0.70
3. Sedation and pain relief during transport	94.6	4.55 $\pm$ 0.60	86.9	4.33 $\pm$ 0.77
4. Impact of transfer on babies with birth-related brain injury	83.7	4.31 $\pm$ 0.79	90.9	4.44 $\pm$ 0.69
5. Optimal temperature management during transfer	85.5	4.18 $\pm$ 0.77	86.9	4.27 $\pm$ 0.78
6. Dealing with bereavement and death in transport	87.3	4.44 $\pm$ 0.76	83.8	4.21 $\pm$ 0.93
7. Invasive ventilation techniques during transport	92.7	4.49 $\pm$ 0.64	80.8	4.11 $\pm$ 0.82
8. Long term neurological outcomes for transported babies	74.5	4.22 $\pm$ 0.88	86.9	4.22 $\pm$ 0.72
9. Impact of vibration exposure during transfer	76.4	4.05 $\pm$ 0.97	85.9	4.22 $\pm$ 0.76
10. Exploration of timely in utero transfer	80.0	4.27 $\pm$ 0.91	82.8	4.28 $\pm$ 0.90
11. Assessments methods for babies' stress and discomfort during transfer	92.7	4.49 $\pm$ 0.69	74.7	3.96 $\pm$ 0.95
12. Ambulance design exclusive to neonatal transport	80	4.20 $\pm$ 0.99	81.8	4.14 $\pm$ 0.81
13. Development of better restraining systems (safety harness) for the baby	74.6	4.15 $\pm$ 0.85	83.8	4.21 $\pm$ 0.79
14. Effects of acceleration and deceleration forces to babies during neonatal transfer	70.9	4.04 $\pm$ 0.99	85.8	4.24 $\pm$ 0.74
15. Respiratory outcomes for transported preterm babies	90.9	4.44 $\pm$ 0.76	74.7	4.01 $\pm$ 0.89
16. Carbon dioxide monitoring in transport	76.4	4.18 $\pm$ 0.91	81.8	4.07 $\pm$ 0.75
17. Family support away from home for those with transferred babies	89.1	4.40 $\pm$ 0.83	73.7	3.92 $\pm$ 0.95
18. Impact of noise exposure during transfer	65.5	3.95 $\pm$ 0.93	85.9	4.26 $\pm$ 0.80
19. Use of non-invasive ventilation such as CPAP and high flow during transport	83.6	4.29 $\pm$ 0.79	73.7	3.94 $\pm$ 0.86
20. Outcomes for babies transferred for surgical management	78.2	4.27 $\pm$ 0.85	76.8	3.92 $\pm$ 0.88
21. Mental health issues associated with families of transported babies	76.3	4.05 $\pm$ 0.95	75.8	3.90 $\pm$ 0.92
22. Benchmarking system for important measures/outcomes in neonatal transport	65.5	3.91 $\pm$ 0.87	80.8	3.98 $\pm$ 0.86

Table. Phase 2 survey, Comparison of parent and healthcare professionals scores (Percentage score  $\geq 4$  and Mean $\pm$ SD) of the 22 research priorities that met consensus after analysis of n=154 survey responses.

Table. Phase 2 survey, Comparison of parent and healthcare professionals scores (Percentage score  $\geq 4$  and Mean $\pm$ SD) of the 22 research priorities that met consensus after analysis of n=154 survey responses.

None declared



## ID 293. Finding Balance between deliberation and intuition in decision-making at the limit of viability: a qualitative Dutch interview study

**Miss Angret De Boer**<sup>1,2</sup>, Mrs. Lien De Proost<sup>3,4</sup>, Dr. Marieke de Vries<sup>5</sup>, Dr. Marije Hogeveen<sup>2</sup>, Prof. dr. Martine C. de Vries<sup>4,6</sup>, Dr. E. Joanne Verweij<sup>1</sup>, Dr. Rosa Geurtzen<sup>2</sup>

<sup>1</sup>Department of Obstetrics and Gynecology, Leiden University Medical Center, Leiden, the Netherlands, <sup>2</sup>Department of Neonatology, Amalia Children's Hospital, Radboud University Medical Center, Nijmegen, the Netherlands, <sup>3</sup>Department of Obstetrics and Gynecology, Erasmus Medical Centre, Rotterdam, the Netherlands, <sup>4</sup>Department of Medical Ethics and Law, Leiden University Medical Center, Leiden, the Netherlands, <sup>5</sup>Institute for Computing and Information Sciences (iCIS), Radboud University Nijmegen, Nijmegen, The Netherlands, <sup>6</sup>Department of Pediatrics, Leiden University Medical Center, Leiden, the Netherlands

Background and aim: When extremely premature birth is imminent, a complex decision must be made regarding the infant's treatment directly after birth. A shared decision-making approach exploring parental values is recommended. Next to more rational deliberation, intuition and feelings play an important role. Therefore, this study aims to gain further insight into (I) whether parents base their decision on intuition and feelings, rational deliberation, or both (II) which values are important for parents in decision-making at the limit of viability and (III) how to best clarify those values during prenatal counselling.

Methods: A semi-structured qualitative interview study was conducted with experienced parents. They were invited through purposive sampling to include

perspectives of parents with different experiences and backgrounds. Interviews were recorded, transcribed and a thematic analysis was performed by two researchers.

Results: Between September 2022 and April 2023, 19 interviews were performed. All experienced an imminent extremely preterm birth (23–26 weeks GA) in the period 2009–2022, both palliative comfort care and intensive care treatment decisions were made and the outcomes varied. Some did eventually not deliver extremely preterm but >26 weeks.

Initial analysis showed variation in themes on what was considered important in decision–making, such as ‘giving a chance’, ‘potential disabilities’, ‘our own happiness’ and ‘quality of life’. Most parents based their decision mostly on intuition and feelings instead of deliberating their values. They indicated that emotions and intuition were inevitable in a challenging situation like imminent extremely premature birth, which did not negatively influence their decision–making. Lastly, parents provided suggestions for value clarification during counselling, such as ‘just ask parents about what they value in life’ and ‘include social work in counselling’.

Conclusion: Parents discussed various values and acknowledged a significant role for emotions and intuition in their decision–making at the limit of viability. Gaining a deeper understanding of parental considerations and feelings during this decision, and how to clarify what is important to them, may lead to improvement of prenatal counselling.

None declared

## ID 544. Translating an “App” predicting survival and disability in infants born extremely preterm into clinical practice

**Doctor Rosemarie Anne Boland**<sup>1,2,3</sup>, Professor Jeanie Cheong<sup>1,2,4</sup>, Associate Professor Michael Stewart<sup>1,3,5</sup>, Dr Stefan Kane<sup>2,6</sup>, Professor Lex Doyle<sup>1,2</sup>

<sup>1</sup>Clinical Sciences, Murdoch Children's Research Institute, Parkville, Australia,

<sup>2</sup>Department of Obstetrics and Gynaecology, University of Melbourne, Parkville,

Australia , <sup>3</sup>Paediatric Infant Perinatal Emergency, Retrieval, Royal Children's Hospital ,

Parkville, Australia , <sup>4</sup>Neonatal Services, Royal Women's Hospital, Parkville, Australia,

<sup>5</sup>Department of Paediatrics, University of Melbourne, Parkville, Australia , <sup>6</sup>Department of Maternal Fetal Medicine, Royal Women's Hospital, Parkville, Australia

### BACKGROUND

We have shown in two previous surveys that clinicians grossly overestimate mortality and disability rates in infants born extremely preterm. Consequently, we developed NIC-PREDICT: a Smartphone application (“app”) and web-based tool (NIC-PREDICT: <https://nic-predict.com.au/>) that predicts infant mortality, and survival with and without major disability at 8 years in infants born 23–27 weeks’ gestation. The aim of this study was to determine if clinicians could predict outcome in these infants more accurately using NIC-PREDICT.

### METHODS

The NIC-PREDICT app was released for clinical use in the state of Victoria on 17/7/2021. We sent an electronic survey to midwives, nurses, obstetricians, and neonatologists working in tertiary and non-tertiary hospitals in Victoria in 2022. Clinicians were asked to use the NIC-PREDICT app to estimate the three mutually exclusive outcomes of 1) infant mortality, 2) survival with major disability, and 3) survival without major disability for six different scenarios where a liveborn infant was

offered active care after birth. The proportions who completed the survey (responded to all six scenarios) and the proportions of those who were able to use the app correctly and provided 100% accurate results for all scenarios were determined. Estimates of the three outcomes were compared with true rates.

## RESULTS

A total of 85 clinicians responded, but only 70 (82%) completed the survey. Of the 70 who completed the survey, overall accuracy was 76% (321/420) for the 6 scenarios. Mortality overall was overestimated by only 0.7% (95% CI -0.7, 2.1), which was a substantial improvement on the previous surveys in 2010 (6.7%, 95% CI 3.7, 9.7) and 2020 (14.4%, 95% CI 12.3, 16.6). Survival with no disability overall was underestimated by only -0.7% (95% CI -3.0, 1.7). However, survival with disability was overestimated by 4.9% (95% CI 1.7, 8.0)  $p=0.003$ .

## CONCLUSION

Most perinatal clinicians who responded can correctly use the NIC-PREDICT app to predict expected outcomes in infants born extremely preterm who are offered active care. However, further training is needed to ensure all perinatal clinicians who are likely to use NIC-PREDICT are able to use it correctly. Undue pessimism about major disability remains an ongoing concern.





<https://nic-predict.com.au/>



NIC-PREDICT web-based platform and Smartphone application (app)

NIC-PREDICT web-based platform and Smartphone application (app)

The authors have no conflict of interest to declare





## ID 514. Enhancing Decision-Making in Neonatal Intensive Care Units: A Clinical Decision System for Early Prediction of Neonatal Mortality and Length of Stay

**Professor Mohammad Reza Zarkesh**<sup>1</sup>, doctor Farzaneh kermani<sup>2</sup>, Mr. Alireza Borhani<sup>3</sup>, doctor Abbas Sheikhtaheri<sup>4</sup>

<sup>1</sup>Yas Hospital Complex/tehran University Of Medical Sciences, Tehran, Iran, <sup>2</sup>Health Information Technology Department, School of Allied Medical Sciences, Semnan University of Medical sciences, Tehran, Iran, <sup>3</sup>independent researcher, Tehran, Iran,

<sup>4</sup>Department of Health Information Management, School of Health Management and Information Sciences, Iran University of Medical Sciences,, Tehran, Iran

**Background:** The use of early predictive models for neonatal mortality and Length of Stay (LOS) in Neonatal Intensive Care Units (NICUs) greatly enhances decision-making capabilities. We developed an intelligent system that employs the "Case-Based Reasoning" (CBR) methodology to effectively predict neonatal mortality and LOS.

**Methods:** The web-based CBR system, based on K-Nearest Neighborhood (KNN) algorithm, was developed to predict neonatal mortality and LOS. A dataset of 1682 neonates, consisting 17 variables for mortality and 13 variables for LOS prediction, was used in the development process. The system's performance was evaluated using 336 retrospectively collected data. Furthermore, the system was successfully implemented and externally validated in a NICU.

**Results:** In the internal validation, the system showed a high accuracy of 97.02% and an F-score of 0.984 for mortality prediction in the balanced case base. The RMSE



for LOS was 4.78 days. The external validation on the balanced case base, showed a significant accuracy of 98.91% and F-score of 0.993 for mortality prediction. The RMSE for LOS was 3.27 days. This system is available at <http://neonatalcdss.ir/>  
Conclusion: The positive results observed in terms of performance showed that this system can be effectively employed to enhance neonatal care.

Keywords: Neonatal mortality, Length of Stay, Neonatal Intensive Care Units (NICUs), Artificial intelligence, Case-Based Reasoning, Clinical decision support system

None declared.