

# Identifying neonatal transport research priorities: a modified Delphi consensus

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## **Abstract**

### **Objectives**

With increasing advances in neonatal transport, a focused research strategy is required to increase the evidence base towards providing optimal care. We aimed to identify the most important neonatal transport research questions as prioritised by parents and healthcare professionals (HCPs).

### **Design**

Key stakeholders participated in a modified three-stage Delphi consensus process. Research questions were identified and submitted through two survey stages before the final priority setting workshop.

### **Participants**

Parents of babies who received neonatal care, neonatal HCPs and stakeholders.

### **Outcome**

Identify the top ten research priorities for neonatal transport.

### **Results**

Overall, 269 survey responses from HCPs/stakeholders (n=161) and parents (n=108) were analysed from two survey rounds. Consensus was reached on 22 of 43 research priorities for the final priority setting workshop. The agreed top research priorities covered the domains of: 1. Pain assessment and management, 2. Long-term neurological outcomes, 3. Impact of transfer on birth-related brain injury, 4. Investigating risk of transport, 5. Safety restraints for infants, 6. Optimal temperature management, 7. Respiratory management and outcomes, 8. Benchmarking of important of transport measures, 9. Understanding transport environmental exposures, 10. Mental Health and burden of transfer on families.

**Conclusion:**

We have identified the top research questions for neonatal transport through an extensive process actively engaging parents, HCPs and key stakeholders. Targeted funding and research resources, directed towards addressing these prioritised research areas, will inform evidence-based practices and international frameworks specific to neonatal transport, helping minimise research waste and ultimately improve outcomes for these high-risk infants and their families.

Word count 248

### **What we already know**

- In the UK, over 15,000 neonatal interhospital transfers occur annually, including 2000 high-risk neurocritical care transfers.
- Neonatal transport services have advanced in recent years; however, marked variations in delivery, standards and practices exist.
- Currently, neonatal transport research lacks agreed priorities important to all stakeholders.

### **What this study adds**

- Using a structured approach, we have co-developed and identified the most important neonatal transport research priorities important to parents and healthcare professionals.

### **How this study might affect research, practice, or policy**

- Prioritising research will guide resources to address key knowledge gaps within neonatal transport and will minimise research waste.
- Increasing evidence-based neonatal transport practice could improve outcomes for infants already of greater risk of neonatal mortality and brain injury.

## Introduction

Over the last 20 years, neonatal transport services have adapted to the centralisation of specialist neonatal intensive care (1, 2). Advances in neonatal transport have enabled retrieval teams to provide critical care during transfer of high-risk infants (3). Critical care neonatal transport has developed into a highly specialised service, requiring evidence-based transport practices to improve infant outcomes, which are measured against standardised international frameworks (4, 5). Despite these advances, infants undergoing interhospital transfer are at an increased risk of severe brain injury and mortality (6-9) .

In the UK, approximately 20 infants per 1000 live births require interhospital transfer with varying medical complexities (10) and similar demand is reported in other high-income countries such as Spain, Canada, and Australia (11-14). Globally, neonatal transport teams are increasingly defining specifications and infrastructure requirements for their services, as well as reporting quality and safety metrics (11, 15, 16). Since 2012, the UK-Neonatal Transport Group (UK-NTG) has reported against a nationally agreed transport dataset (17). These datasets can help identify trends and challenges in neonatal transport (11, 16) but a priority-driven and focused approach is required to explore neonatal transport research knowledge gaps.

The World Health Organisation emphasizes quality of care, needs to be “effective” and “people-centred”, meaning practices should be evidence based and responsive to individual preferences and current needs (18). The James Lind Alliance (JLA) guidance is a recognised method for healthcare research priority setting and with an emphasis on patient and public involvement (PPI) (19, 20). Modified Delphi methodology, guided by the JLA principles, has become an accepted and cost-effective method for achieving consensus in healthcare research priority setting (21, 22). Utilising a modified Delphi consensus approach, we aimed to identify the top 10 research priorities for neonatal transport and explore any similarities and differences between parent and healthcare professional (HCPs) perspectives.

## Methods

Using the principles outlined by the JLA guidance for priority setting (19, 23), a modified Delphi process was constructed and delivered over a 2-year period between 2019 and 2021 (Figure 1).

An expert steering group consisted of neonatal transport representatives from the UK-Neonatal transport group (UK-NTG), UK-Neonatal Transport Research Collaborative (UK-NTRC), and the research group from University of Nottingham who formulated the study protocol (*Supplementary file, Figure 1*). Following a summary review of the current literature relating to neonatal transport and previous UK-NTG service lead meetings and datasets (24), the expert group identified 43 research priority areas (*Supplementary file*) for stakeholders. These were grouped under five key themes below:

- Service delivery, communication, and data sharing
- Patient management during transfer
- Transport environment/safety for staff and patients
- Transport patient outcomes
- Patient and parent orientated care

### *Phase 1 and 2 survey construction and dissemination.*

The Jisc online survey platform Version 2 (25) was used for construction and dissemination of the survey. Surveys were disseminated to HCPs through the UK-NTG, UK-NTRC, and British Association of Perinatal Medicine (BAPM). Surveys were disseminated to parents with prior experience of neonatal care through the Bliss charity, local parent groups and social media.

Phase 1 included 43 research priorities, divided into five themed areas. Respondents ranked each priority against a 5-point Likert scale; 1=not important, 2=least important, 3=neither, 4=important, 5=very important. Under each themed subsection, the respondent was given the opportunity to volunteer their own research question using a free text response

(*Supplementary file*). The Phase 1 survey design and the priorities disseminated can be found in the *supplementary file* along with the method used to manage free text responses (*Supplementary file, Table 3*). For a research priority to continue in the Delphi process they needed to achieve a percentage agreement of > 75% of respondents scoring  $\geq 4$ .

Priorities meeting the agreement criteria and the additional research priorities generated from the free text responses were included in Phase 2, where they were ranked against the same 5-point Likert scale described above. The online survey software does not offer automated randomisation of the question order, so research priorities were coded numerically and randomly selected to determine their order of presentation within the survey.

Characteristic of HCP's role and parental experience of neonatal care were collected in both surveys and participants responses were anonymised.

In partnership with the Bliss Charity, both phases of parent surveys were re-phrased ensuring appropriate use of lay terminology to define any medical terms where necessary.

#### *Survey analysis*

Survey results were exported into Microsoft Excel and analysed in Prism GraphPad (V9, Dotmatics). Scores from the parent and HCP surveys were combined for analysis.

Percentage of participants scoring  $\geq 4$  and mean  $\pm$  SD were calculated. Parent and HCP scoring were compared across survey rounds, to identify shared or differing perspectives.

#### *Final Delphi consensus workshop*

HCPs were approached through the UK-NTRC, UK-NTG, and parents through the Bliss charity social media and local parent groups to attend the workshop. Each delegate received a preparation pack prior to the workshop. The final consensus workshop was held on the Microsoft Teams platform and used breakout rooms to facilitate group discussions. The Delphi workshop programme was structured based on the JLA online workshop guidance (23) (outlined in the *Supplementary file*). Each group was led by a facilitator and an observer

unaffiliated to the core research group. The facilitator led and moderated group discussions, while the observer supported the facilitator, documented key discussion points, and compiled ranking scores.

The workshop consisted of two rounds of group ranking and two plenary sessions. Three groups containing balanced numbers of HCPs and parents were assigned before commencing the workshop (Figure 1). Delegates were mixed into new groups in the second ranking round to ensure different viewpoints were heard by all participants. Each group ranked priorities from 1 to 22, 1 being most important and gaining the highest score. Group scores were aggregated and averaged at each ranking round and presented to all delegates within the plenary sessions. The scores following the second ranking round were discussed in a final plenary session with all delegates to reach consensus on the top 10 priorities. In the event of a disagreement, an online polling tool was used to facilitate live voting to aid reaching an agreement in ranking.

A final report of the workshop was sent to all delegates to review key discussions and the agreed research priorities (*Supplementary file*). Delegates were invited to complete a post workshop feedback questionnaire.

## **Results**

Two survey participants did not complete the consent to use their responses leaving a total of 269 responses from HCPs (n=161) and parents (n=108) over the first two phases of the survey (Figure 1). The survey participants included doctors (21.6%), nurses (25.3%), advanced neonatal nurse practitioner's (4.1%), neonatal transport service leads (3.7%), transport allied HCPs (4.8%), parents of infants who underwent neonatal transfer (35.7%) and parents with infants who had neonatal care but did not need transfer (4.1%).

### **Phase 1 and 2 surveys**

For Phase 1 (115 responses), 23 of 43 research priorities met the agreement criteria (Table 1). Free text responses (n=36) created six additional priorities which were included in Phase



2. Additional questions included areas of enteral feeding, developmental positioning aids, infection, comparing outcomes of preterm and term infants, impact of acceleration and deceleration forces and the role of humidification of inhaled gases in transfer.

*(Supplementary file, Table 3).*

In Phase 2 (154 responses), 22 of 29 research priorities met the agreement criteria (Table 1). The top five priorities identified in Phase 2 had >85% of survey respondent score  $\geq 4$ . Research around dealing with death and bereavement increased from rank 17 of 43 in Phase 1 to the sixth most important priority in Phase 2.

### **Parent and HCP prioritisation**

The transition of parent and HCP scoring of research priorities across survey rounds is illustrated in Figure 2. Both parents and HCPs ranking in prioritisation aligned in 26 of 43 (60%) priorities in Phase 1 and 16 of 29 (55%) priorities in Phase 2.

For infant outcomes in Phase 1, parents and HCPs shared agreement and prioritised respiratory outcomes in preterm infants undergoing transfer and long-term neurological outcomes. However, in Phase 2 their prioritisation was divided, with parents favouring respiratory outcomes compared to HCPs who favoured long term neurological outcomes.

Parent and HCP alignment varied across research prioritisations in Phase 2 (Figure 3).

#### *Parent and HCP shared priority*

The top five research priorities identified in Phase 2 covered areas of transport risk, thermoregulation, pain and sedation, and impact of transfer on infants with birth-related brain injury. These were all highly ranked by parents and HCPs with >80% of each cohort scoring  $\geq 4$  in both surveys (Figure 2 and 3), indicating stability in their scoring across survey rounds. They also agreed that safety alert systems, differences between term and preterm outcomes, and humidification of inhaled gases were low priority areas.

### *Parent high priority*

There were eight areas that parents rated highly but HCPs ranked lower. These focused on elements of family integrated care, comfort of the infant during transfer and familiar aspects of neonatal care such as respiratory and feeding management. Four of these priorities did not meet the agreement criteria in Phase 2.

### *HCP high priority*

Five areas were highly ranked by HCPs with parents ranking them as low priority. These included a number of environmental exposures such as noise, development of safety harnesses, and benchmarking of transport measures.

These differing areas of prioritisation observed amongst both groups remained consistent across Phase 1 and 2.

### **Final Delphi workshop**

Twenty-two research priorities reached the final workshop stage. After two rounds of ranking by the 18 delegates, mean aggregate scores were presented in the final plenary session for discussion (*Supplementary file, Table 7*). The highest scoring priorities following both ranking rounds were sedation and pain management and its assessment during transfer. In contrast, priorities of exclusive ambulance design for neonatal transport and death and bereavement in transport were identified as the least important. Within the final plenary discussions, some overlapping research priorities were rephrased and merged following group consensus. Details of these discussions are outlined in the *Supplementary file, Final Delphi workshop report*. Consensus was reached and the final top ten neonatal transport research priorities were agreed (Table 2).

## Discussion

The recent emergence and importance of neonatal inter-hospital transfer, as a key part of the neonatal care pathway globally (1, 2, 5, 12, 16), has resulted in an increase in research studies, particularly observational studies exploring transport metrics and outcomes (6, 11, 14, 16, 26, 27). These studies have highlighted the many unique elements of the transport pathway that differ from in-hospital neonatal care (6-9, 28). This study is the first step in identifying the important research priorities of neonatal transport based on the consensus agreement from a large range of HCPs, parents, and other stakeholders. The established, robust methodology has allowed the top 10 research priorities to be identified providing a focus for funders and researchers to tackle the most critical knowledge gaps, and help address current challenges of neonatal transport teams worldwide (3, 11, 12, 14, 16, 29, 30).

Our Delphi approach has allowed us to capture the input from over 250 HCPs, parents, and key stakeholders to reach this consensus agreement. Emerging themes include outcomes of transported infants, improving safety of neonatal transport, benchmarking metrics, temperature and respiratory management during transport, environmental hazards, and the impact on families. Parents favoured family/infant centric priorities which focused on areas most familiar to them and their child's neonatal journey from the in-hospital environment, whilst HCP prioritisation lent towards service outcomes, patient safety and environmental exposures. These differences likely stem from an individual's experience, knowledge, and exposure within the neonatal transport setting (31). For example, only approximately 29% of parents travel in the ambulance with their infant in the UK (10) and so their time on the neonatal unit may well dominate their experience and shape their priority focus.

A notable strength of our study is the substantial input from parents. It was a crucial aspect of our approach to ensure active PPI throughout all elements of the study. We took great care to ensure parent voices were heard at each stage of the study, through careful questionnaire design and advocating their perspectives through Bliss Charity representation. Obtaining equal weighting of parent and healthcare perspectives in the surveys was

challenging due to the notable difference in participant numbers in Phase 2 , which risked parent underrepresentation (19, 32). Active parent involvement in the Delphi workshop helped mitigate this. Workshop facilitators of the group sessions highlighted that the discussions between parents and HCPs were dynamic and that they shared and listened to each other's viewpoints, experiences, and knowledge respectfully. Facilitating collaborative discussions between parents and HCPs enabled parents and HCPs to reach an agreement with their scoring and establish a shared approach towards priority ranking.

Delphi techniques used to reach consensus in healthcare vary in quality and validity (22). Using our modified JLA approach we successfully achieved our studies objectives. The stability in priority scoring observed through survey rounds justify the appropriateness of our 5-point Likert scale and percentage agreement criteria (33-36). We are unable to fully mitigate for question order and selection bias (32, 34), nor for individuals' perceptions of ranking and understanding of research priorities, recognised limitations of e-Delphi processes (36-38).

Our study was planned before the COVID-19 pandemic and so needed adaptation with restrictions that were put in place. The use of an online platform for the workshop, replacing a traditional face-to-face session, has been successfully adopted by other priority-setting working groups such as diabetes in pregnancy and occupational therapy (39, 40) using a similar JLA format to this study (23). Being aware of potential limitations of online platforms; strategic use of breakout rooms, rotating group membership, and polling tools aided participant interaction and inclusivity. This was well-received by delegates and reflected in their post-workshop feedback.

## **Conclusion**

This is the first Delphi consensus identifying the top ten research priority areas for neonatal transport. Active engagement of parent perspectives, alongside healthcare professionals, has played a vital role in our robust priority setting approach, generating holistic research priorities relevant to the needs of service providers and their users'. With the increasingly critical role inter-hospital transport plays on the neonatal care pathway, these co-developed research priorities will provide guidance for funders and researchers, to tackle the most pressing knowledge gaps in this understudied domain. Informing evidence-based practices and standardised international frameworks for neonatal transport will improve care for these high-risk infants and their families.

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## **Collaborators:**

On behalf of the UK-Neonatal Transport Research Collaborative (UK-NTRC), an affiliated group of the UK-Neonatal Transport Group (UK-NTG): Sarah Davidson, Allan Jackson, Samantha O'Hare, Santosh Pattnayak, Catherine Rutherford, Nandiran Ratnaval, Rob Tinnion, Alison Walker.

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### **Author contributions**

AM, DS, SO conceptualised and formulated the study protocol. AM led the implementation and conducted each stage of study and the data analysis. The first draft of manuscript was written by AM, and reviewed and edited by AL, SO and DS. All authors approved the final version for publication. DS is the guarantor of the study.

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### **Conflict of interests:**

DS is the research lead for the UK-NTG and the UK-NTRC.

### **Ethics Statement and Approval**

Research Ethics Committee approval was not required as this is a priority setting partnership study and no participants were recruited.

### **Data availability statement:**

All data are included in this manuscript or supplement.

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Expert steering group meeting  
Literature review, identify gaps in knowledge  
43 research priorities formulated

36 free text responses  
generated and  
screened\*

6 new research priorities  
formed

**Phase 1 survey**  
43 research priorities  
115 responses

23 research priorities met percentage  
agreement criteria

**Parent (n=53)**  
Parent of infant who was transferred (47)  
Parent of infant not transferred (5)  
Previous NICU patient (1)

**Healthcare professional (n=62)**  
Neonatal/transport consultant (18)  
Neonatal/transport nurse (26)  
Neonatal transport service lead (2)  
Senior doctor (4)  
ANNP (5)  
Transport call handler (3)  
Neonatal transport matron (1)  
Paramedic (3)

**Phase 2 survey**  
29 research priorities.  
154 responses

22 research priorities met percentage  
agreement criteria

**Parent (n=55)**  
Parent of infant who was transferred (49)  
Parent of infant not transferred (6)  
Excluded (1)

**Healthcare professional (n=99)**  
Neonatal/transport consultant (24)  
Neonatal/transport nurse (41)  
Neonatal transport service lead (8)  
Senior doctor (12)  
ANNP (6)  
Transport service manager (1)  
Paramedic (6)  
Excluded (1)

**Phase 3 Delphi workshop**  
22 research priorities discussed  
24 delegates planned 18 attended

Parents (5)  
Bliss Representative (1)  
Neonatal transport service lead (2)  
Neonatal transport consultant (6)  
ANNP (2)  
Neonatal transport nurse (2)

**Top 10 Research priorities agreed**

**Figure 1.** Flowchart of the modified Delphi consensus to identifying research priorities for neonatal transport, presenting each stage in terms of research priorities and participants involvement. \*Following James Lind Alliance guidance; each response was verified against relevant databases to assess whether it was a valid research question. Responses were excluded if responses/research priorities were duplicated or were related to existing priorities.

Neonatal transport services lead: neonatal consultants who are head of a transport service.

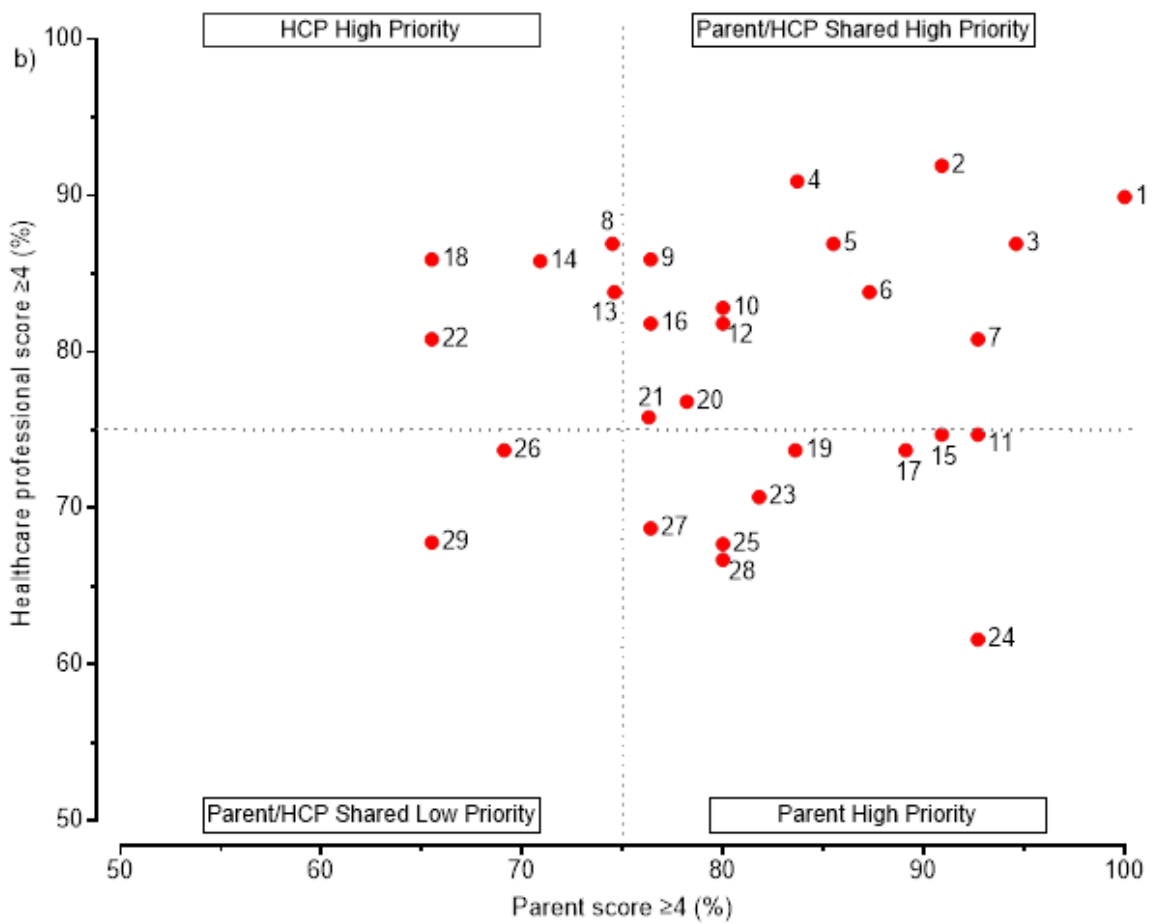
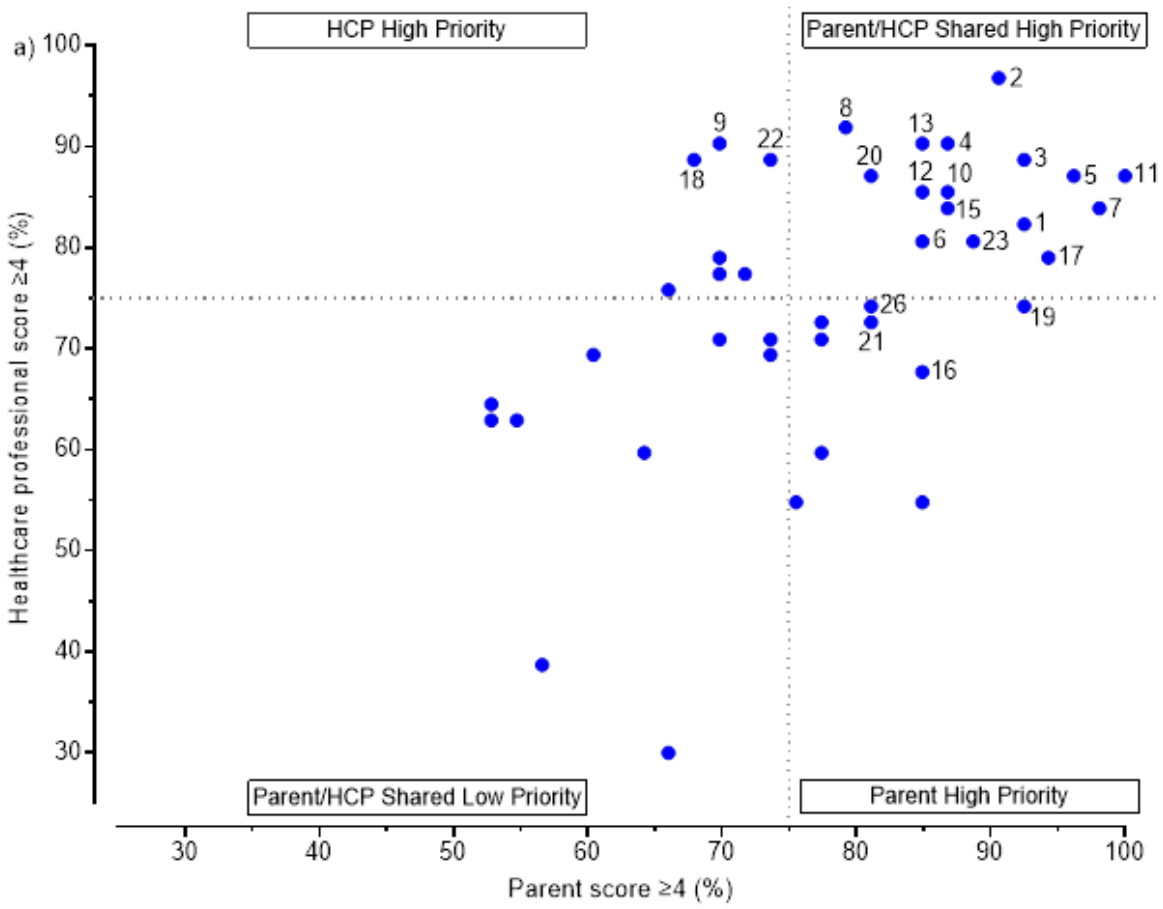
Senior doctors: neonatal transport fellows or specialist trainee doctors. Transport allied healthcare professionals: paramedics, transport service managers and call handlers.

Abbreviations: Neonatal intensive care unit (NICU), Advanced Neonatal Nurse Practitioner (ANNP).

	Phase 1	Phase 2
Neonatal transport research priorities Phase 2 survey ranking	n=115 % score ≥4 (rank)	n=154 % score ≥4
1. Preventing harm associated with equipment failure in neonatal transport	87 (8)	94
2. Investigating the risk of neonatal transport	94 (1)	92
3. Sedation and pain relief during transport	90 (4)	90
4. Impact of transfer on babies with birth-related brain injury	89 (6)	88
5. Optimal temperature management during transfer	91 (3)	86
6. Dealing with bereavement and death in transport	83 (17)	85
7. Invasive ventilation techniques during transport	90 (5)	85
8. Long term neurological outcomes for transported babies	86 (9)	82
9. Impact of vibration exposure during transfer	81 (19)	82
10. Exploration of timely in utero transfer	86 (11)	83
11. Assessments methods for babies' stress and discomfort during transfer	93 (2)	82
12. Ambulance design exclusive to neonatal transport	85 (13)	82
13. Development of better restraining systems (safety harness) for the baby	88 (7)	80
14. Effects of acceleration and deceleration forces to babies during neonatal transfer	-	80
15. Respiratory outcomes for transported preterm babies	85 (12)	80
16. Carbon dioxide monitoring in transport	76 (23)	80
17. Family support away from home for those with transferred babies	86 (10)	79
18. Impact of noise exposure during transfer	79 (20)	79
19. Use of non-invasive ventilation such as CPAP and high flow during transport	83 (16)	77
20. Outcomes for babies transferred for surgical management	84 (15)	77
21. Mental health issues associated with families of transported babies	76 (22)	76
22. Benchmarking system for important measures/outcomes in neonatal transport	82 (18)	75
23. Bonding between mother and babies following transport	83 (14)	75
24. The risk/rate of infection in those babies that are transferred	-	73
25. Enteral feeding during transfer; the risks, safety, and outcomes for babies	-	72
26. Development of a shared safety alert system for neonatal transport	77 (21)	72
27. Impact of humidification(warmed) inhaled gases in neonatal transfers	-	72
28. The use of developmental positioning aids in neonatal transport	-	72
29. Outcomes in preterm babies versus term babies that are transferred	-	67

**Table 1.** The 29 research priorities assessed across Phase 1 and Phase 2 surveys in (Phase 2) rank order, presenting the percentage of survey respondents scoring ≥4 for each research priority.

CPAP, Continuous positive airway pressure.



**Figure 2.** Scatter plots presenting the distribution of the percentage of parents (x axis) against percentage of healthcare professionals (HCPs) (y axis) scoring  $\geq 4$ . 2a) Phase 1 survey results of 43 research priorities assessed, parents' (n=53) and HCPs (n=62). 2b) Phase 2 survey results of 29 research priorities, parents' (n=55) and HCPs (n=99). Research priorities labelled 1-29 in Figure 2 a and b refer to research priorities assessed in Phase 2 as referenced in (Table 1). Shared high priority is defined as  $>75\%$  of both cohorts scoring  $\geq 4$ , shared low priority is defined as  $<75\%$  of both cohorts scoring  $\geq 4$ . Differing perspectives in prioritisation are defined as those where one cohort has  $<75\%$  scoring  $\geq 4$  with a percentage difference between cohorts of  $\geq 10\%$ .

**HCP High Priority**

- Long-term neurological outcomes for transported babies (HCP=87%, Parent=74%)
- Development of better restraint system (safety harness) for the baby (HCP=84%, Parent=75%)
- Effects of acceleration and deceleration forces to babies during neonatal transfer (HCP=86%, Parent=71%)
- Impact of noise exposure during transfer (HCP=86%, Parent=66%)
- Benchmarking system for important measures/outcomes in neonatal transport (HCP=81%, Parent=66%)

**Parent/HCP Shared High Priority**

- Preventing harm associated with equipment failure (HCP=90%, Parent=100%)
- Investigating the risk of neonatal transport (HCP=92%, Parent=91%)
- Sedation and pain relief during transport (HCP=87%, Parent=95%)
- Impact of transfer on babies with birth-related brain injury (HCP=84%, Parent=91%)
- Optimal temperature management during transfer (HCP=87%, Parent=86%)
- Dealing with bereavement and death in transport (HCP=84%, Parent=87%)
- Invasive ventilation techniques during transport (HCP=81%, Parent=93%)
- Exploration of timely in utero transfer (HCP=83%, Parent=80%)
- Ambulance design exclusive to neonatal transport (HCP=82%, Parent=80%)
- Carbon dioxide monitoring in transport (HCP=82%, Parent=76%)
- Outcomes for babies transferred for surgical management (HCP=77%, Parent=78%)
- Mental health issues associated with families of transported babies (HCP=76%, Parent=78%)
- Impact of vibration exposure during transfer (HCP=86%, Parent=76%)

**Parent/ HCP Shared Low Priority**

- Development of a shared safety alert system for neonatal transport\* (HCP=74 %, Parent=69%)
- Outcomes in preterm babies versus term babies that are transferred\* (HCP=68%, Parent=66%)
- Impact of humidification of inhaled gases in neonatal transfers\* (HCP= 69%, Parent=76%)

**Parent High Priority**

- Assessments methods for babies' stress and discomfort during transfer (HCP=75%, Parent=93%)
- Family support away from home for those with transferred babies (HCP=74%, Parent=89%)
- Use of non-invasive ventilation such as CPAP during transfer (HCP=74%, Parent=84%)
- Respiratory outcomes for transported preterm babies (HCP=75%, Parent=91%)
- The use of developmental positioning aids in neonatal transport\* (HCP=67%, Parent=80%)
- Enteral feeding during transfer, the risks, safety, and outcomes for babies\*(HCP= 68%, Parent=80%)
- Bonding between mother and babies following transport\* (HCP=71%, Parent=82%)
- The risk/rate of infection in those babies that are transferred\* (HCP=62%, Parent=93%)



**Figure 3.** The shared and differing perspectives of parents (n=55) and healthcare care professionals (n=99) Phase 2 survey responses. Shared high priority is defined as >75% of both cohort scoring  $\geq 4$ , shared low priority is defined as <75% of both cohorts scoring  $\geq 4$ . Differing perspectives in prioritisation were defined as those where one cohort has <75% scoring  $\geq 4$  with a percentage difference between cohorts of  $\geq 10\%$ . \* Research priorities that did not meet the Delphi agreement criteria in Phase 2. HCP=Healthcare Professional.

<b>Top Ten Neonatal Transport Research Priorities</b>	
<b>1.</b>	<b>What are the best assessment tools and management strategies for pain and stress during neonatal transport?</b>
Original wording: Assessment and management methods for infant sedation and pain (stress and discomfort) in neonatal transport	
<b>2.</b>	<b>How are the long-term outcomes for transported newborns different compared to non-transported infants?</b>
Original wording: Long term neurological outcomes for transported babies	
<b>3.</b>	<b>What is the impact of transport on infants with birth related brain injury (such as hypoxic ischaemic encephalopathy)?</b>
Original wording: Impact of transfer on babies with birth related brain injury	
<b>4.</b>	<b>How do we best identify and reduce the risks of neonatal transport for infants and staff?</b>
Original wording: Investigating the risks of neonatal transport	
<b>5.</b>	<b>What is the best way to safely restrain infants for transport?</b>
Original wording: Development of better restraining systems (safety harness) for the baby	
<b>6.</b>	<b>What is the ideal temperature range and management of infants during transport?</b>
Original wording: Optimal temperature management during transfers	
<b>7.</b>	<b>What is the optimal respiratory management for transporting infants, especially high-risk preterm infants, and how does this affect their outcome?</b>
Original wording: Invasive and non-invasive respiratory management and the long-term respiratory outcomes of transported infants	
<b>8.</b>	<b>What are the important measures for neonatal transport services and how do we record them?</b>
Original wording: Benchmarking system for important measures/outcomes in neonatal transport	
<b>9.</b>	<b>What are the adverse effects on infants to exposures in the transport environment (such as noise and vibration forces) and how can these be reduced?</b>
Original wording: Understanding the neonatal transport environmental exposures (e.g., noise, vibration, acceleration, and deceleration forces) and their impact on the infant	
<b>10.</b>	<b>What are the additional burdens on families of transported infants (such as mental wellbeing) and how can these best be supported?</b>
Original wording: Mental health issues and additional burden on families of transported infants	

**Table 2.** Finalised top ten research priorities for neonatal transport. Original wording of research priority is below the suggested question for each research priority.



# **Identifying neonatal transport research priorities: a modified Delphi consensus**

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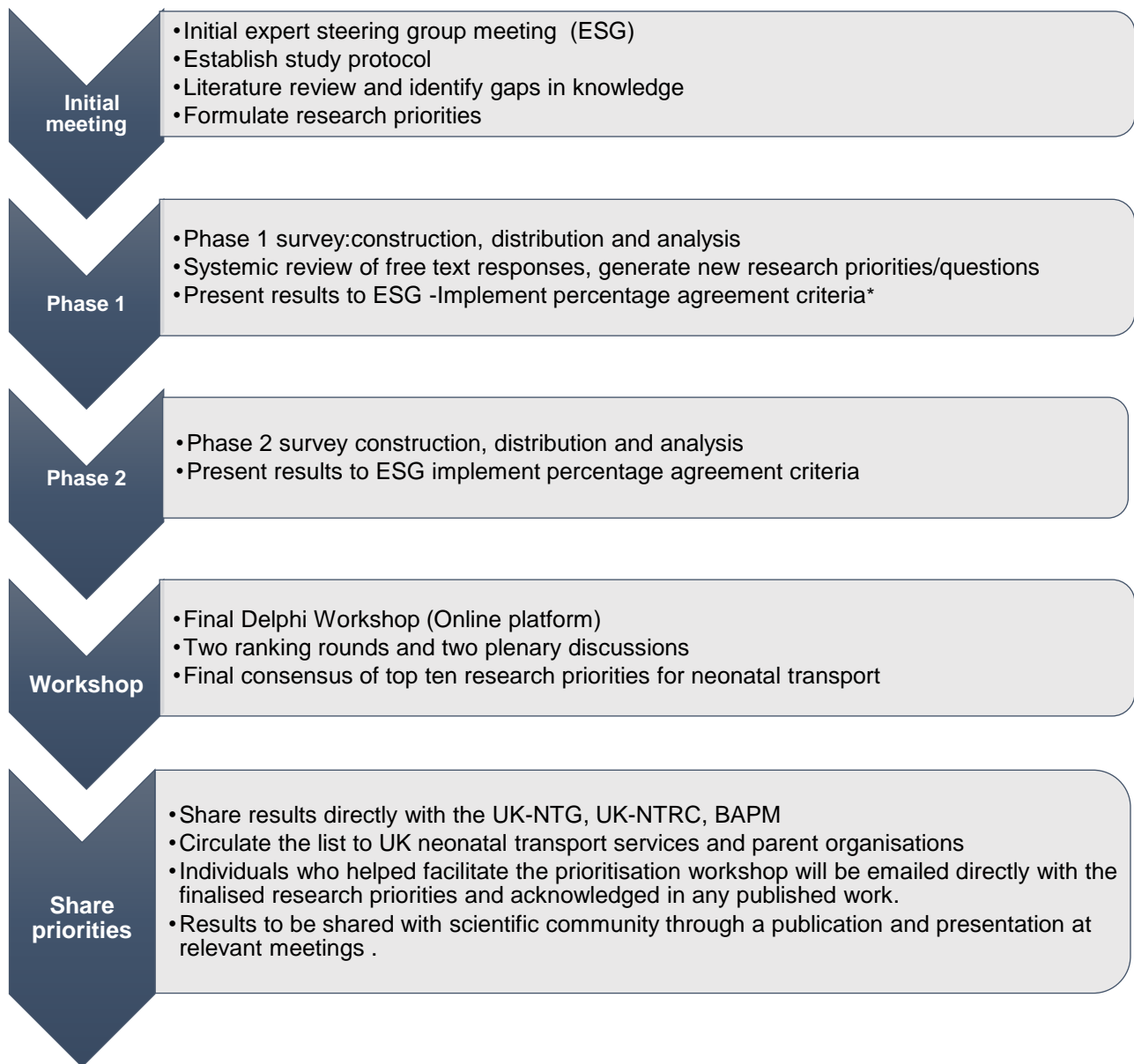
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## **Supplementary Study File Content.**

- 1. Outline of study protocol**
- 2. Phase 1 survey-Question and survey construction**
- 3. Phase 1 survey-Results**
- 4. Phase 2 survey-Construction**
- 5. Phase 2 Survey- Results**
- 6. Final Delphi workshop- Programme**
  
- 7. Final Delphi workshop and summary report**
- 8. Key discussions points in plenary sessions about key research priorities.**
- 9. Post workshop feedback questionnaire.**

## Supplementary File

### Outline of study protocol



**Figure 1** Modified Delphi summary of study protocol. ESG, Expert steering group. Percentage agreement criteria > 75% of respondent scoring  $\geq 4$

## **Phase 1 survey- Question and survey construction.**

There were 5 themes and 43 research priority questions.

### **1.Service delivery, communication, and data sharing**

Definition: This can relate to how services are managed, staffing structure, training performance and target setting. In addition, it refers to communication with different teams, other colleagues, and with other networks. It also refers to methods of sharing information about service, performance, research, and safety.

- a) Using video technology for transport referrals or in ambulance communication/advice
- b) Development of a shared safety alert system for neonatal transport
- c) Using technology during transfers (e.g., tablets) to improve the collection of transport data
- d) Prospective national database of neonatal transfers
- e) Benchmarking system for important measures/outcomes
- f) Outcomes of dedicated neonatal and combined neonatal/paediatric transport teams
- g) Utilising non-neonatal staff to conduct neonatal transfers.
- h) Human factors/simulation training in transport
- i) Assessment of Nurse led neonatal transfers.
- j) Exploration of timely in-utero transfers (moving mums prior to birth)
- k) Use of air transport in the UK

### **2. Patient management during transfer.**

Definition: This can refer to the medical management, transport equipment and monitoring, or understanding the physical impact associated with transfers.

- a) Transport risk scoring tools
- b) Carbon dioxide monitoring in transport
- c) Non-invasive measures of neurological (brain) function during transport e.g. monitoring electrical seizures (fits)
- d) Optimal temperature management during transfers
- e) Invasive ventilation techniques during transport
- f) Sedation and pain relief during transport
- g) Investigating the risks of neonatal transport
- h) Use of non-invasive ventilation such as CPAP and High flow during transport

### **3.Transport environment/safety for staff and patients**

Definition: This refers to the environment of transport and its exposures it places on the baby but also the staff, and the unique situations it can create. It also refers to safety issues related to patient, staff and equipment.

- a) Impact of noise exposure during transfer
- b) Impact of vibration exposure during transfer
- c) Ambulance design for exclusive neonatal transport
- d) Assessing the comfort and stress of staff during transfers
- e) Development of better restraining systems (safety harness) for the baby
- f) Route mapping to improve transfer efficiency and safety
- g) Preventing harm associated with equipment failure
- h) Well-being programs to support staff
- i) Assessment methods for patient stress/discomfort

#### **4. Transported patient outcomes**

Definition: This refers to the long-term outcomes of those babies that we transfer, i.e., meeting their childhood developmental milestones, length of hospital stay, are they more likely to go home with oxygen etc.

- a) Long-term neurological/developmental outcomes for transport babies
- b) Respiratory (breathing) outcomes for transported preterm babies
- c) Outcomes for babies transferred for surgical management
- d) Impact of transfer on babies with birth-related brain injuries.
- e) Health-economic (cost-effectiveness) assessment of inter-hospital transport
- f) Short and medium-term biomarker (biological measures) outcomes of transported babies
- g) Standardized outcome dataset for transported babies

#### **5. Patient and parent orientated care**

Definition: This refers to the patient and parent experiences and their perspectives around the process of transport.

- a) Assessment of telecommunication between parents and transport team
- b) Mental health issues associated families of transferred babies
- c) Prior to birth transfers vs after birth transfers a parent perspective
- d) Predicting time to delivery to aid in-utero transfer for mothers in preterm labour
- e) Family support away from home for those with transferred babies
- f) Dealing with bereavement/death in transport
- g) Bonding between mother and baby following transfer
- h) Evaluation of transport with parent's present

Figure 2: Example of JISC online survey(1) presentation. PDF link of the Phase 1 survey sent to healthcare professionals and parents.

## Page 2: Service delivery, communication and data Sharing

Definition: This can relate to how services are managed, staffing structure, training performance and target setting. In addition, refers to communication with different teams, other colleagues, and with other networks. It also refers to methods of sharing information about service, performance, research and safety.

Please score the research questions below on their level of importance to you. Answer as many questions as possible. \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 11 answer(s).

	Not important	Least important	Neutral	Important	Very Important
a. Using video technology for transport referrals or in ambulance communication/advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Development of a shared safety alert system for neonatal transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Using technology during transfers (e.g. tablets) to improve the collection of transport data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Prospective national database of neonatal transfers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Benchmarking system for important measures/outcomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



f. Outcomes of dedicated neonatal and combined neonatal/paediatric transport teams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Utilising non-neonatal staff to conduct neonatal transfers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Human factors /simulation training in transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Assessment of Nurse led neonatal transfers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Exploration of timely in-utero transfers (moving mums prior to birth)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Use of air transport in the UK	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any important research questions you would like answering in relation to **service delivery, communication and data sharing** not mentioned above? If so please tell us in the box below.

## Phase 1 survey-Results

**Table 1.** Combined results. Phase 1 survey (n=115) responses of 43 research priorities, presenting percentage score  $\geq 4$ , Mean and SD. Highlighted in grey those that did not meet consensus.

Research Priorities	Score $\geq 4$ (%)	Mean	SD
1. Investigating the risks of neonatal transport	93.9	4.50	0.61
2. Assessment methods for babies' stress and discomfort during transfer	93.0	4.49	0.68
3. Optimal temperature management during transfers	91.3	4.37	0.73
4. Sedation and pain relief during transport	90.4	4.39	0.72
5. Invasive ventilation techniques during transport	90.4	4.37	0.74
6. Impact of transfer on babies with birth related brain injury.	88.7	4.34	0.72
7. Development of better restraining systems (safety harness) for the baby.	87.8	4.39	0.77
8. Preventing harm associated with equipment failure	87.0	4.38	0.83
9. Long-term neurological outcomes for transport babies	86.1	4.35	0.74
10. Family support away from home for those with transferred babies	86.1	4.23	0.76
11. Exploration of timely in-utero transfers (moving mums prior to birth)	86.1	4.15	0.97
12. Respiratory (breathing) outcomes for transported preterm babies	85.2	4.30	0.82
13. Ambulance design for exclusive neonatal transport	85.2	4.30	0.86
14. Bonding between mother and baby following transfer	84.3	4.31	0.91
15. Outcomes for babies transferred for surgical management	84.3	4.27	0.81
16. Use of non-invasive ventilation such as CPAP and High flow during transport.	82.6	4.22	0.89
17. Dealing with bereavement/death in transport	82.6	4.20	0.95
18. Benchmarking system for important measures/outcomes	81.7	4.12	0.82
19. Impact of vibration exposure during transfer.	80.9	4.17	0.90
20. Impact of noise exposure during transfer	79.1	4.03	0.94
21. Development of a shared safety alert system for neonatal transport	77.4	4.05	0.81
22. Mental health issues associated families of transferred babies	76.5	4.05	0.87
23. Carbon dioxide monitoring in transport	75.7	3.99	0.95
24. Assessment of Nurse led neonatal transfers	74.8	3.80	0.84
25. Evaluation of transport with parent's present	74.8	4.00	0.92
26. Assessing the comfort and stress of staff during transfers.	74.8	3.97	0.83
27. Transport risk scoring tools	73.9	3.96	0.82
28. Standardized outcome dataset for transported babies	73.9	3.91	0.89
29. Outcomes of dedicated neonatal and combined neonatal/Paediatrics transport teams	72.2	3.83	0.99
30. Well-being programmes to support staff.	71.3	3.90	0.89
31. Using technology during transfers (e.g. tablets) to improve the collection of transport data	71.3	3.88	0.87
32. Human factors /simulation training in transport	71.3	3.84	0.90
33. Predicting time to delivery to aid in-utero transfer for mothers in preterm labour	70.4	4.02	0.85
34. Non-invasive measures of neurological(brain) function during transport e.g. monitoring electrical seizures (fits)	68.7	3.85	0.85
35. Use of air transport in the UK	67.8	3.73	1.06
36. Prior to birth transfers vs after birth transfers a parent perspective	65.2	3.77	0.89
37. Route mapping to improve transfer efficiency and safety	64.3	3.78	0.93
38. Assessment of telecommunication between parents and transport team	61.7	3.74	0.86
39. Prospective national database of neonatal transfers	59.1	3.68	0.95
40. Short and medium-term biomarker (biological measures) outcomes of transported babies	59.1	3.59	0.92
41. Health-economic (cost-effectiveness) assessment of inter-hospital transport	58.3	3.55	0.99
42. Using video technology for transport referrals or in ambulance communication/advice	47.0	3.33	0.97
43. Utilising non-neonatal staff to conduct neonatal transfers	41.7	3.11	1.23

**Table 2** Phase 1 survey result comparing parent and healthcare professional survey score. Grey highlighted priorities did not met the percentage agreement criteria in the combined analysis

Research Priorities in Rank order	Parent (n=53)		Healthcare professional (n=62)	
	Score ≥4 (%)	Mean ± SD	Score≥4 (%)	Mean± SD
1. Investigating the risks of neonatal transport	90.6	4.47±0.67	96.8	4.53±0.56
2. Assessment methods for patient stress and discomfort during transfer	100	4.72±0.45	87.1	4.29±0.78
3. Optimal temperature management during transfers	96.2	4.40±0.57	87.1	4.35±0.85
4. Invasive ventilation techniques during transport	98.1	4.57±0.54	83.9	4.21±0.85
5. Sedation and pain relief during transport	92.5	4.51±0.64	88.7	4.29±0.78
6. Impact of transfer on babies with birth related brain injuries.	86.8	4.30±0.75	90.3	4.37±0.71
7. Development of better restraining systems (safety harness) for the baby.	84.9	4.25±0.76	90.3	4.52±0.76
8. Preventing harm associated with equipment failure	92.5	4.60±0.69	82.3	4.19±0.90
9. Long-term neurological outcomes for transport babies	79.2	4.21±0.82	91.9	4.47±0.65
10. Exploration of timely in-utero transfers (moving mums prior to birth)	86.8	4.15±0.89	85.5	4.15±1.04
11. Family support away from home for those with transferred babies	94.3	4.38±0.60	79.0	4.11±0.87
12. Ambulance design for exclusive neonatal transport	84.9	4.36±0.83	85.5	4.24±0.88
13. Respiratory (breathing) outcomes for transported preterm babies	86.8	4.38±0.84	83.9	4.23±0.78
14. Bonding between mother and baby following transfer	88.7	4.47±0.89	80.6	4.18±0.92
15. Outcomes for babies transferred for surgical management	81.1	4.26±0.86	87.1	4.27±0.77
16. Use of non-invasive ventilation such as CPAP and High flow during transport.	92.5	4.43±0.69	74.2	4.03±0.99
17. Dealing with bereavement/death in transport	84.9	4.28±0.89	80.6	4.13±1.0
18. Benchmarking system for important measures/outcomes	73.6	3.96±0.81	88.7	4.26±0.81
19. Impact of vibration exposure during transfer.	69.8	3.92±0.94	90.3	4.37±0.81
20. Impact of noise exposure during transfer	67.9	3.74±1.0	88.7	4.27±0.81
21. Development of a shared safety alert system for neonatal transport	81.1	3.74±1	74.2	3.95±0.88
22. Mental health issues associated families of transferred babies	81.1	4.11±0.85	72.6	4.0±0.89
23. Carbon dioxide monitoring in transport	84.9	4.26±0.71	67.7	3.76±1.07
24. Assessment of Nurse led neonatal transfers	77.4	3.96±0.71	72.6	3.66±0.92
25. Evaluation of transport with parent's present	69.8	3.83±0.99	79.0	4.16±0.83
26. Assessing the comfort and stress of staff during transfers.	71.7	3.89±0.78	77.4	4.05±0.88
27. Transport risk scoring tools	77.4	4.09±0.74	70.9	3.84±0.87
28. Standardized outcome dataset for transported babies	69.8	3.77±0.93	77.4	4.03±0.85
29. Outcomes of dedicated neonatal and combined neonatal/paediatric transport teams	73.6	3.89±0.87	70.9	3.79±1.09
30. Well-being programmes to support staff.	73.6	3.91±0.77	69.4	3.90±0.99
31. Using technology during transfers (e.g. tablets) to improve the collection of transport data	66.0	3.81±0.83	75.8	3.94±0.90
32. Human factors /simulation training in transport	66.0	3.75±0.73	75.8	3.92±1.03
33. Predicting time to delivery to aid in-utero transfer for mothers in preterm labour	69.8	3.98±0.87	70.9	4.05±0.84
34. Non-invasive measures of neurological(brain) function during transport e.g monitoring electrical seizures (fits)	84.9	4.30±0.72	54.8	3.47± 0.76
35. Use of air transport in the UK	77.4	4.0±0.85	59.7	3.5±1.17
36. Prior to birth transfers vs after birth transfers a parent perspective	60.4	3.58±0.91	69.4	3.94±0.85
37. Route mapping to improve transfer efficiency and safety	75.5	3.98±0.84	54.8	3.61±0.98
38. Assessment of telecommunication between parents and transport team	64.2	3.72±0.89	59.7	3.76±0.84
39. Prospective national database of neonatal transfers	54.7	3.58±0.93	62.9	3.76±0.84
40. Short and medium-term biomarker (biological measures) outcomes of transported babies	52.8	3.47±0.93	64.5	3.69± 0.89
41. Health-economic (cost-effectiveness) assessment of inter-hospital transport	52.8	3.36±1.1	62.9	3.71±0.88
42. Using video technology for transport referrals or in ambulance communication/advice	56.6	3.81±0.92	38.7	3.18±1.06
43. Utilising non-neonatal staff to conduct neonatal transfers	66.0	3.81±0.92	30.0	2.52±1.16

## Phase 1 survey- Management and review of free text responses

Free text responses generated from the Phase 1 survey were reviewed in line with the James Lind alliance guidance (2).

For each response, the following was assessed:

- Is there a research question to be answered?
- If it is not a research question provide a reason
- Exclude similar responses and responses already included within the original Phase 1 survey
- Verifying the responses felt to be unanswered by checking relevant databases (The Cochrane Database of Systematic Reviews, Medline, NICE guidelines, SIGN clinical guidelines, and Relevant Royal Colleges' guidance)

36 free text responses were generated from the Phase 1 survey and six responses were identified as true additional research questions/priorities to be taken forward to the Phase 2 survey listed below:

1. Enteral feeding during transfers; the risks, safety, and outcomes for babies
2. The use of developmental positioning aids in neonatal transport
3. Impact of humidification of inhaled gases in neonatal transfers
4. Effects of acceleration and deceleration forces to babies during neonatal transfer.
5. The risk/rate of infection in those babies that are transferred
6. Outcomes in preterm babies versus term babies that are transferred.

**Table 3.** Summaries the assessment of each free text response in align with the James Lind Alliance recommendations.

No	Free text responses Parent responses (1-12) Healthcare professional responses (13-36)	Is there a research question? (Yes or no)	Why this is not a research question?	Is the question already included ?	If included which topic does it relate to	Evidence available	Generated research question.
1	Better information on the hospital being transferred to. Having had to do this twice already and having no idea on each hospital with regards to parking, how to find the unit or what to expect on arrival it is extremely difficult and overwhelming when already under pressure in an intense, difficult and emotional experience and journey.	No	This is a practical problem and can be answered by a simple quality improvement project	n/a	n/a	n/a	n/a
2	What conditions / symptoms dictate what care professionals are present for neonate transfers. Sometimes only a nurse is required but other times registrars or consultants are present.	No	This refers to standards outlined by the BAPM, and NTG guidance and also each individual neonatal networks policy	Yes	Benchmarking for important measures/outcomes  The use of transport risk scoring tools  Assessment of Nurse led neonatal transfers	n/a	n/a
3	Bonding also with the father. In all things mothers are given tip status which makes a lot of sense, but fathers are also very important and often overlooked	Yes	n/a	Yes	Family support away from home for those transferred babies	n/a	

4	When mother and child both patients and transferred separately, being separated from baby for hours with no communication as to how baby is faring and the emotional impact of the anxiety on the parents	Yes	n/a	Yes	Mental health issues in families associated with the transfer of babies.  Assessing the use of telecommunication between parent's transport team  Evaluation of transport parents present.	n/a	n/a
5	Assessing hygiene standards of harness equipment etc. to reduce risk of infection	Yes	n/a	No	n/a	No evidence found	The risk/rate of infection in those babies that are transferred
6	Temperature of patient. My twins were put together in an incubator and got too hot.	Yes	n/a	Yes	Optimal temperature management during transfers	n/a	n/a
7	Driver awareness of all potential procedures carried out during patient transfers and  How driving style can impact or support these.	No  Yes	This would be address through an educational package.	n/a  Yes	n/a  Route mapping to improve transfer efficiency and safety	n/a  n/a	n/a  n/a
8	The safety and environment for both babies and staff is very important. I know this due to my daughter needing a procedure done at the roadside and the impact this had on both.	Yes	n/a	Yes	Preventing harm associated with equipment failure.  Investigating the risk of neonatal transport	n/a	n/a

9	If a patients gestation affects outcomes. Is it higher risk for a more preterm baby rather than a baby that is closer to term?	Yes		No	n/a	No evidence found.  Predominant research just looks at outcomes of preterm neonates that require early inter-hospital transfer:  -Helenius <i>et al.</i> Association of early postnatal transfer and birth outside a tertiary hospital with mortality and severe brain injury in extremely preterm infants: observational cohort study with propensity score matching <i>BMJ</i> 2019; 367: l5678 doi:10.1136/bmj.l5678	Outcomes in preterm babies versus term babies that are transferred
10	Impact of feeding prior to transfer. How long after feeding should transfers take place?	Yes		No	n/a	No evidence found from searched databases	Enteral feeding during transfer, the risks and safety, and outcomes for babies
11	Our experience and seeing other transports the hospital staff often cause delays to transport crew leaving. For us this meant our baby missed a feed which felt wrong and worrying when so small and vulnerable. Also, the crew didn't know where to go at destination hospital which also wasted time	No	This requires service improvement and collaboration with NICU.	n/a	n/a	n/a	n/a

12	Real time tracking of all transport assets to manage neonatal transport area or region efficiently.	Yes		yes	Using technology during transfers (e.g., tablets) to improve the collection of transport data (standards).  Route mapping to improve transfer efficiency and safety.	n/a	n/a
13	Costs (including time) spent on Neonatal Transport research 1) clearly recorded and 2) matched against documented or at least a plausible improvement of service or a progress in any defined way.	Yes  Yes		Yes  Yes	Health-economic (cost-effectiveness) assessment of inter-hospital transport  Benchmarking system for important measures/outcomes	n/a	n/a
14	Using conference calling for transport referrals Assessment of ANNP or Doctor led transfers	yes		Yes	Using video technology for transport referrals or in ambulance communication/advice	n/a	n/a
15	Use of technology to manage repatriation/elective workloads - particularly for teams split over multiple sites (e.g. a virtual whiteboard style system). Use of technology on journeys to track teams/update status of journey without requiring phoning in - possibility for all teams in a network to see each other's location & status when receiving referrals when not in base.	yes		Yes	Using technology during transfers (e.g., tablets) to improve the collection of transport data (standards).  Route mapping to improve transfer efficiency and safety.  Using video technology for transport referrals or in ambulance communication/advice	n/a	n/a



16	How service overruns are managed	no	This can be answered through service evaluation across neonatal networks and does not require research.	N/a	n/a	n/a	n/a
17	Involvement of parents during transport - either in the vehicle or my phone/VC	Yes		Yes	Evaluation of transport with parent's present  Assessing use of telecommunication between parents and transport team	n/a	n/a
18	Active cooling on transfer and Nitric delivery.	yes  very broad statement		Yes	Impact of transfer on babies with birth related brain injuries		
19	Positioning during transport	Yes	n/a	No	n/a	The evidence is orientated with the setting of NICU setting, however not in the neonatal transport.  Papers highlight roll of developmental assessment tools with relation to positioning. Below:  Altimer <i>et al</i> . The Neonatal Integrative Developmental Care	The use of development positioning aids in neonatal transport

						<p>Model: Advanced Clinical Applications of the Seven Core Measures for Neuroprotective Family-centred Developmental Care. Newborn and Infant nursing reviews. 2016 <a href="https://doi.org/10.1053/j.nai.nr.2016.09.030">https://doi.org/10.1053/j.nai.nr.2016.09.030</a></p> <p>Madlinger-Lewis <i>et al.</i> The effects of alternative positioning on preterm infants in the neonatal intensive care unit: A randomized clinical trial, Research in Developmental Disabilities, Volume 35, Issue 2,2014, Pages 490-497, ISSN 0891-4222, <a href="https://doi.org/10.1016/j.ridd.2013.11.019">https://doi.org/10.1016/j.ridd.2013.11.019</a></p> <p>Could this be implemented in a neonatal transport.</p>	
20	QU	Unable to process lack info	n/a	n/a	n/a	n/a	n/a
21	Accuracy of differing measures of CO2 monitoring during transport - end-tidal vs transcutaneous, particularly in neonatal transfers.	Yes		Yes	Carbon dioxide monitoring during transfer	There are a lot of small sized observational studies in this area, a multi-centred study is required to standardise and evidence clinical practice changes.	n/a

	Best approach for feeding prior to/during transport for stable repatriation journeys, particularly lengthy ones, balance of nutrition, need for invasive interventions and safety during transfer.	Yes		As above refer 11	n/a	As above refer to question 11	As above, refer to question 11.
22	enteral feeding pre/during/post transfers in non-acute transfers?	yes	n/a	As above 11	n/a	As above refer to question 11	As above, refer to question 11
23	Would like more research based on effectiveness of our equipment. e.g how effective are the current transport incubators on the market?	yes	n/a	Yes	Preventing harm associated with equipment failure.  Optimal temperature management during transfers  Development of a shared (between transport networks) safety alert system for neonatal transport	n/a	n/a
24	Standardising encephalopathy assessment during transport	yes	n/a	Yes	Impact of transfer in babies with birth-related brain injury	n/a	n/a
25	Risk of feeds before/during transfers and the effect of stopping feeds on how unsettled babies are during transport	yes		As above 11		As above	As above refer to question 11
26	Clinical value of environmental humidity in transport of VLBW newborn <1w old.	Yes	n/a	Yes	Humidity as part of the optimal temperature management and fluid management of a neonate. This can be addressed	In relation to environmental humidity, it is a well-known from NICU studies and RCN guidance of the importance of humidity in <	Impact of humidification inhaled gases in neonatal transfers

	Clinical value of inhaled gas humidity in intubated newborn.	Yes		No	under the topic included Optimal temperature management during transfers.	<p>1-week VLBW. Can be addressed under the topic of optimal temperature management during transfers.</p> <p><a href="https://www.rch.org.au/rch_cpg/hospital_clinical_guide_line_index/Environmental_humidity_for_premature_neonates/">https://www.rch.org.au/rch_cpg/hospital_clinical_guide_line_index/Environmental_humidity_for_premature_neonates/</a> Date accessed: 20.04.21.</p> <p>Sinclair, L &amp; Sinn, J (2009), 'Higher versus Lower Humidity for the Prevention of Morbidity and Mortality in Preterm Infants in Incubators', Intervention Protocol, Cochrane Neonatal Group.</p> <p>No current evidence available around the humification of gases for ventilated inter hospital transfers and there are varying practices by transport services on its application. There is already significant evidence in the neonatal intensive care setting for its benefit highlighted below:</p>	
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						<p>Meyer MP, Owen LS, Te Pas AB. Use of Heated Humidified Gases for Early Stabilization of Preterm Infants: A Meta-Analysis. <i>Front Pediatr.</i> 2018; 6:319. Published 2018 Oct 25. doi:10.3389/fped.2018.00319</p> <p>Doctor TN, Foster JP, Stewart A, Tan K, Todd DA, McGrory L. Heated and humidified inspired gas through heated humidifiers in comparison to non-heated and non-humidified gas in hospitalised neonates receiving respiratory support. <i>Cochrane Database Syst Rev.</i> 2017;2017(2):CD012549. Published 2017 Feb 24. doi:10.1002/14651858.CD012549</p>	
27	Comparison of job attributes justifying early retirement in some professions with the profession of neonatologist covering neonatal ITU and/or	no	This is service evaluation and not a research question	n/a	n/a	n/a	n/a

	transport (hands on delivered service).						
28	Impact of noise and vibration with (unnecessary) blue light transfers should staff be offered breaks on long transfers?  If we have one ambulance driver how long should they be allowed to drive?	Yes  No	  This is based on ambulance service guidance	Yes	Impact of vibration exposure during transfer	n/a	n/a
29	Ambulance design for patient and staff comfort and safety	yes		Yes	Ambulance design for exclusive neonatal transport  Assessing the comfort and stress of staff during transfers  Assessment methods for babies' stress and discomfort during transport	n/a	n/a
30	Combining some of these themes: what effect ambulance design and  positioning of patient (i.e., bulkhead/lateral forwards/lateral rear) has on both vibration exposure	Yes  Yes	n/a  n/a	Yes  Yes	Ambulance design for exclusive neonatal transport  Could be incorporated within the topic of impact of vibration exposure during transfer.		

	but acceleration/deceleration forces and the physiological effects of these.	yes	n/a	No	n/a	No evidence found in relevant databases searched	Effects of acceleration and deceleration (speed) forces to babies during neonatal transfers
31	How are developmental care positioning aids used during transfer?	Yes		No	No	As above refer to 19	The use of developmental positioning aids in neonatal transport
32	pretransfer stability and assessed likelihood of deterioration/failure to progress and communication to parents and receiving unit of these assessments	Yes		Yes	The use of transport risk scoring tools	n/a	n/a
33	Length of separation of parents from babies transferred, and impact of breastmilk expressing/ breastfeeding success	Yes	n/a	Yes	Bonding between mother and baby following transfers	Well evidenced that long separation from the baby that breast milk supply slows in mums.  Example below:  Yang, Y., Brandon, D., Lu, H. <i>et al.</i> Breastfeeding experiences and perspectives on support among Chinese mothers separated from their hospitalized preterm infants: a qualitative study. <i>Int Breastfeed J</i> 14, 45 (2019). <a href="https://doi.org/10.1186/s13006-019-0242">https://doi.org/10.1186/s13006-019-0242</a>	n/a

34	Some of those questions appear as Quality improvement initiative.	n/a	Statement not a question	n/a	n/a	n/a	n/a
35	Involving parents in handovers at both referring and receiving hospitals: communication of important family-centred information as well as effects on parents' perspective on the transfer and possible reduction in later adverse effects on mental health/bonding.	yes	n/a	yes	Use of telecommunication between parents and transport teams.  Mental health issues in families, associated with the transfer of babies	n/a	n/a
36	arrangements for car parking at receiving unit for transferred parents and information about facilities there including for siblings	No	This refers to practical dilemmas of individual hospital which research will not be able to impact	n/a	n/a	n/a	n/a



## Phase 2 Survey- Survey Construction

Consisted of total of 29 research priorities carried forward from the Phase 1 survey and free text responses generated. The questions in the online survey were coded numerically and randomly selected to determine their order of presentation within the survey.

Figure 3. Snapshot of Phase 2 survey presentation on JISC online survey(1).

### Research questions

Please score each research question below on their level of importance to you. \*

*Required*

Please don't select more than 1 answer(s) per row.

Please select at least 29 answer(s).

	Not important	Least Important	Neutral	Important	Very important
Preventing harm associated with equipment failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health issues associated to families of transported babies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with bereavement and death in transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use of non-invasive ventilation such as CPAP and high flow during transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enteral feeding during transfer; risk safety, outcomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Development of better restraining (safety harness) for the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Phase 2 Survey-Results

**Table 4.** Phase 2 survey n=154 responses. 22 research priorities met percentage agreement criteria (>75% of respondents scoring  $\geq 4$ ). Research priorities that didn't not met this criteria, are depicted below the red line and highlighted in grey.

Research Priorities	Score $\geq 4$ (%)	Mean score	SD
1. Preventing harm associated with equipment failure in neonatal transport	93.5	4.62	0.69
2. Investigating the risks of neonatal transport	91.6	4.39	0.71
3. Sedation and pain relief during transport	89.6	4.41	0.72
4. Impact of transfer on babies with birth related brain injury	88.3	4.39	0.73
5. Optimal temperature management during transfers	86.4	4.24	0.78
6. Dealing with bereavement and death in transport	85.1	4.29	0.88
7. Invasive ventilation techniques during transport	85.1	4.25	0.78
8. Long term neurological outcomes for transported babies	82.5	4.22	0.78
9. Impact of vibration exposure during transfer	82.5	4.16	0.84
10. Exploration of timely in utero transfer (moving mums prior to birth)	81.8	4.28	0.9
11. Assessment methods for babies' stress and discomfort during transport	81.7	4.15	0.89
12. Ambulance design for exclusive neonatal transport	81.7	4.16	0.87
13. Development of better restraining systems (safety harness) for the baby	80.5	4.19	0.81
14. Effects of acceleration and deceleration (speed) forces to babies during neonatal transfer	80.5	4.17	0.85
15. Respiratory(breathing) outcomes for transported preterm babies	80.5	4.16	0.87
16. Carbon dioxide monitoring in transport	79.9	4.11	0.80
17. Family support away from home for those transferred babies	79.2	4.09	0.94
18. Impact of noise exposure during transfer	78.6	4.15	0.86
19. Use of non-invasive ventilation such as CPAP and high flow during transport	77.3	4.06	0.84
20. Outcomes for babies transferred for surgical management	77.3	4.04	0.88
21. Mental health issues associated to families of transported babies	76.0	3.95	0.93
22. Benchmarking system for 4 measures/outcomes in neonatal transport	75.3	3.95	0.86
23. Bonding between mother and babies following transport	74.7	4.0	0.97
24. The risk/rate of infection in those babies that are transferred	72.7	3.92	0.91
25. Enteral feeding during transfer; the risks, safety and outcomes for babies	72.1	3.88	0.96
26. Development of a shared safety alert system for neonatal transport	72.1	4	0.96
27. Impact of humidification(warmed) inhaled gases in neonatal transfers	71.5	3.92	0.82
28. The use of developmental positioning aids in neonatal transport	71.5	3.96	0.91
29. Outcomes in preterm babies versus term babies that are transferred	66.9	3.87	0.98

**Table 5**, Phase 2 survey results, comparing parent (n=55) and healthcare professionals (n=99) survey scores for each of the 29 research priorities assessed. The research priorities highlighted in grey did not meet the percentage agreement criteria and were not take forward to the workshop.

Research priorities	Parent scores (n=55)		Healthcare professional scores (n=99)	
	Score $\geq$ 4 (%)	Mean $\pm$ SD	Score $\geq$ 4 (%)	Mean $\pm$ SD
30. Preventing harm associated with equipment failure in neonatal transport	100	4.80 $\pm$ 0.40	89.9	4.53 $\pm$ 0.80
31. Investigating the risk of neonatal transport	90.9	4.49 $\pm$ 0.72	91.9	4.33 $\pm$ 0.70
32. Sedation and pain relief during transport	94.6	4.55 $\pm$ 0.60	86.9	4.33 $\pm$ 0.77
33. Impact of transfer on babies with birth-related brain injury	83.7	4.31 $\pm$ 0.79	90.9	4.44 $\pm$ 0.69
34. Optimal temperature management during transfer	85.5	4.18 $\pm$ 0.77	86.9	4.27 $\pm$ 0.78
35. Dealing with bereavement and death in transport	87.3	4.44 $\pm$ 0.76	83.8	4.21 $\pm$ 0.93
36. Invasive ventilation techniques during transport	92.7	4.49 $\pm$ 0.64	80.8	4.11 $\pm$ 0.82
37. Long term neurological outcomes for transported babies	74.5	4.22 $\pm$ 0.88	86.9	4.22 $\pm$ 0.72
38. Impact of vibration exposure during transfer	76.4	4.05 $\pm$ 0.97	85.9	4.22 $\pm$ 0.76
39. Exploration of timely in utero transfer	80.0	4.27 $\pm$ 0.91	82.8	4.28 $\pm$ 0.90
40. Assessments methods for babies' stress and discomfort during transfer	92.7	4.49 $\pm$ 0.69	74.7	3.96 $\pm$ 0.95
41. Ambulance design exclusive to neonatal transport	80	4.20 $\pm$ 0.99	81.8	4.14 $\pm$ 0.81
42. Development of better restraining systems (safety harness) for the baby	74.6	4.15 $\pm$ 0.85	83.8	4.21 $\pm$ 0.79
43. 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
44. Respiratory outcomes for transported preterm babies	90.9	4.44 $\pm$ 0.76	74.7	4.01 $\pm$ 0.89
45. Carbon dioxide monitoring in transport	76.4	4.18 $\pm$ 0.91	81.8	4.07 $\pm$ 0.75
46. Family support away from home for those with transferred babies	89.1	4.40 $\pm$ 0.83	73.7	3.92 $\pm$ 0.95
47. Impact of noise exposure during transfer	65.5	3.95 $\pm$ 0.93	85.9	4.26 $\pm$ 0.80
48. 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
49. Outcomes for babies transferred for surgical management	78.2	4.27 $\pm$ 0.85	76.8	3.92 $\pm$ 0.88
50. Mental health issues associated with families of transported babies	76.3	4.05 $\pm$ 0.95	75.8	3.90 $\pm$ 0.92
51. Benchmarking system for important measures/outcomes in neonatal transport	65.5	3.91 $\pm$ 0.87	80.8	3.98 $\pm$ 0.86
52. Bonding between mother and babies following transport	81.8	4.31 $\pm$ 0.92	70.7	3.89 $\pm$ 0.97
53. The risk/rate of infection in those babies that are transferred	92.7	4.51 $\pm$ 0.69	61.6	3.59 $\pm$ 0.85
54. Enteral feeding during transfer; the risks, safety and outcomes for babies	80	4.11 $\pm$ 0.83	67.7	3.76 $\pm$ 1.0
55. Development of a shared safety alert system for neonatal transport	69.1	4.04 $\pm$ 1.04	73.7	3.98 $\pm$ 0.93
56. Impact of humidification(warmed) inhaled gases in neonatal transfers	76.4	4.07 $\pm$ 0.84	68.7	3.83 $\pm$ 0.81
57. The use of developmental positioning aids in neonatal transport	80	4.18 $\pm$ 0.80	66.7	3.84 $\pm$ 0.94
58. Outcomes in preterm babies versus term babies that are transferred	65.5	3.95 $\pm$ 0.93	67.8	3.80 $\pm$ 1.0

## Final Online Delphi workshop- Programme

### IDENTIFYING RESEARCH PRIORITIES FOR NEONATAL TRANSPORT – FINAL WORKSHOP

**Date Monday 6<sup>th</sup> September 2021**

**9.30am to 15:00pm**

Hosted virtually by University of Nottingham

#### Workshop objectives

1. Give an overview of the priority setting process and work so far
2. To reflect on and discuss participants views of the uncertainties shortlisted
3. In groups prioritise the order of the short list
4. Together agree the 10 most important research priorities
5. Consider next steps.

#### Programme timetable

9:15am	Participant registration on MS Teams
9:30 am	Opening sessions <ul style="list-style-type: none"><li>• Welcome and overview of the workshop day (Dr Andy Leslie, Chair)</li><li>• About the project: how it started and where we are today (Dr Don Sharkey)</li><li>• Introduction of short-listed research priorities (Dr Don Sharkey/ Dr Aarti Mistry)</li></ul>
10: 00 am	Breakout session 1: <ul style="list-style-type: none"><li>• Small group discussion of priorities (Group 1, 2, 3)</li></ul>
11:00 am	Coffee break
11:15 am	Breakout session 2: (same group) <ul style="list-style-type: none"><li>• First round of ranking, participants begin to rank the shortlist</li></ul>
12:00 pm	Lunch Break
12:40 pm	Plenary session -aggregate rank and uncertainties presented to all
13:00 pm	Breakout session 3: (New group allocation) <ul style="list-style-type: none"><li>• Second round of prioritisation- revising the shared ranking</li></ul>
13:45 pm	Coffee Break and connect back to plenary session
14:00 pm	Final plenary session <ul style="list-style-type: none"><li>• Aggregate ranking presented - whole group discussion</li><li>• Final ranking and top 10 agreed</li></ul>
14:45 pm	Summary of the day and next steps (Dr Andy Leslie and Dr Don Sharkey)
15:00 pm	Workshop closes -Thank you

### Delphi workshop summary and report

Twenty-two shortlisted research priorities listed below (Table 6) were discussed in the meeting. The ranking score from the Phase 2 survey were given to the delegates prior to the meeting, presenting the parent, healthcare professional and combined rank. These were also presented in the opening presentations.

Ref	Research Priority
A.	Ambulance design for exclusive neonatal transport
B.	Assessment methods for babies' stress and discomfort during transport
C.	Benchmarking system for important measures/outcomes in neonatal transport
D.	Carbon dioxide monitoring in transport
E.	Dealing with bereavement and death in transport
F.	Development of better restraining systems (safety harness) for the baby
G.	Effects of acceleration and deceleration (speed) forces to babies during neonatal transfer
H.	Exploration of timely in utero transfer (moving mums prior to birth)
I.	Family support away from home for those transferred babies
J.	Impact of noise exposure during transfer
K.	Impact of transfer on babies with birth related brain injury
L.	Impact of vibration exposure during transfer
M.	Invasive ventilation techniques during transport
N.	Investigating the risks of neonatal transport
O.	Long term neurological outcomes for transported babies
P.	Mental health issues associated to families of transport babies
Q.	Optimal temperature management during transfers
R.	Outcomes for babies transferred for surgical management
S.	Preventing harm associated with equipment failure in neonatal transport
T.	Respiratory (breathing) outcomes for transported preterm babies
U.	Sedation and pain relief during transport
V.	Use of non-invasive such as CPAP and high flow during transport

**Table 6. 22 Shortlisted research priorities presented for discussion during the workshop.**

During the workshop two rounds of ranking between three groups of healthcare professionals and parent representatives were undertaken in breakout rooms.

After the first round of ranking a decision was made in the first plenary session that the following research priorities:

**B. Assessment methods for babies’ stress and discomfort during transport**

**U. Sedation and pain relief during transport**

Should be consolidated into one research priority this was a consensus established through discussions in all three groups. Therefore, in the final group discussions (breakout session 3), 21 research priorities were discussed for repeat ranking.

The final aggregate ranking was presented to the whole group in the final plenary session shown below in Table 7.

Rank	Ref	Research Priority	Final mean Score
1	B/U	Assessment methods for babies’ stress and discomfort during transport/sedation and pain in transport	21
2	O.	Long term neurological outcomes for transported babies	20
3	K.	Impact of transfer on babies with birth related brain injury	19
4	N.	<b>Investigating the risks of neonatal transport</b>	<b>18</b>
5	F.	Development of better restraining systems (safety harness) for the baby	16
6	Q.	Optimal temperature management during transfers	15
7	M.	<b>Invasive ventilation techniques during transport</b>	<b>15</b>
8	V.	<b>Use of non-invasive such as CPAP and high flow during transport</b>	<b>15</b>
9	T.	<b>Respiratory (breathing) outcomes for transported preterm babies</b>	<b>13</b>
10	C.	Benchmarking system for important measures/outcomes in neonatal transport	12
11	L.	<b>Impact of vibration exposure during transfer</b>	<b>11</b>
12	S.	<b>Preventing harm associated with equipment failure in neonatal transport</b>	<b>11</b>
13	G.	<b>Effects of acceleration and deceleration (speed) forces to babies during neonatal transfer</b>	<b>10</b>
14	J.	<b>Impact of noise exposure during transfer</b>	<b>10</b>
15	P.	<b>Mental health issues associated to families of transport babies</b>	<b>9</b>
16	H.	Exploration of timely in utero transfer (moving mums prior to birth)	8
17	D.	Carbon dioxide monitoring in transport	6
18	R.	Outcomes for babies transferred for surgical management	4
19	I.	<b>Family support away from home for those transferred babies</b>	<b>3</b>
20	A.	Ambulance design for exclusive neonatal transport	2
21	E.	<b>Dealing with bereavement and death in transport</b>	<b>2</b>

**Table 7. Final aggregate ranking after two rounds of ranking, presented in final plenary session to the delegate group.**

## **Key discussion points in plenary sessions about key research priorities - Led by Professor D Sharkey & Dr A Leslie.**

### **1. Research priorities M, V, T discussed highlighted in blue (Table 7):**

These priorities were prominent features in all group discussion sessions. Overall, the delegates felt that these all belonged together. However, it was evident that T specifically referred to preterm respiratory outcomes of babies, whilst M and V were focused on management aspect of respiratory support in transport. It was concluded to combine these into a single research priority that encompassed both management and respiratory outcomes of all transport babies. A vote was performed through MS forms poll and had a 100% consensus from the delegate group was established. The research priority was rephrased to:

### **Invasive and non-invasive respiratory management and the long-term outcomes of transported infants**

### **2. Research priorities: L, G, J highlighted in yellow (Table 7)**

The delegates felt these three research priorities explored a similar theme associated to the transport environment and its potential exposures/stressors. All delegates understood that each priority was exploring a specific stressor, however felt each of them had equal merit and importance that they all needed to be researched. It was therefore agreed that they should be combined under one research priority. These priorities were combined and rephrased below:

### **Understanding the neonatal transport environmental exposures (eg noise, vibration, acceleration and deceleration forces) and their impact on the infant.**

### **3. Research priority N and S highlighted in red (Table 7)**

In the group discussions, delegates felt N was a very broad research priority and needed defining further, i.e. was it referring to the assessment of risk before transport or prevention of harm. In the final plenary session, it was felt the priority S fell under the assessment of risk and could be considered as research question within the broader research priority of N.

### **4. Research priorities: P, I, E highlighted in orange (Table 7)**

In the group discussions, parents were keen this needed to be highly ranked, however from healthcare professional perspective it was deemed to be a low priority as they felt that the transport journey is small part of the parent/neonatal experience and this type of research priority needed to be considered from whole neonatal care pathway perspective. Therefore, we see in the final ranking that I and E rank very lowly out of 21.

Discussion in the plenary session highlighted the importance of the impact that neonatal transport had on the mental health or burden on families. Parent representatives were keen for this to be reflected in the top ten and discussions were had about the importance of understanding of burden versus just mental health issues. There was also shared support from some healthcare professionals which highlighted the importance of such research would inform better implementation of family integrated care in the setting of neonatal transport. As a consequence of the amalgamation of other priorities above, research priority P moved into the top ten, with minor rephrasing to reflect the potential burden transport may pose on families.

### **Menth health issues and additional burden on families of transported infants.**

### **5. Research priority: H**

In the plenary session many delegates were surprised how low this priority ranked. As it was deemed highly important in most groups by both healthcare professionals and parents through the group discussion sessions. However, there was a consensus that this research should be led from an obstetric perspective and not by neonatal transport. It was therefore agreed that whilst this was hugely important it did not need to feature in the final top ten research priorities for neonatal transport.

**Final Agreed Top Ten Research Priorities for Neonatal Transport**

No.	Top Ten Research Priorities for Neonatal Transport
1	<b>Assessment and management methods for infant sedation and pain (stress and discomfort) in neonatal transport</b>
	➤ <i>What are the best assessment tools and management strategies for pain and stress during neonatal transport?</i>
2	<b>Long term neurological outcomes for transported babies</b>
	➤ <i>How are the long-term outcomes for transported newborns different compared to non-transported infants?</i>
3	<b>Impact of transfer on babies with birth related brain injury</b>
	➤ <i>What is the impact of transport on babies with birth related brain injury (such as hypoxic ischaemic encephalopathy)?</i>
4	<b>Investigating the risks of neonatal transport</b>
	➤ <i>How do we best identify and reduce the risks of neonatal transport for babies and staff?</i>
5	<b>Development of better restraining systems (safety harness) for the baby</b>
	➤ <i>What is the best way to safely restrain babies for transport?</i>
6	<b>Optimal temperature management during transfers</b>
	➤ <i>What is the ideal temperature range and management of babies during transport?</i>
7	<b>Invasive and non-invasive respiratory management and the long-term outcomes of transported infants</b>
	➤ <i>What is the optimal respiratory management for transporting infants, especially high-risk preterm infants, and how does this affect their outcome?</i>
8	<b>Benchmarking system for important measures/outcomes in neonatal transport</b>
	➤ <i>What are the important measures for neonatal transport services and how do we record them?</i>
9	<b>Understanding the neonatal transport environmental exposures (e.g., noise, vibration, acceleration and deceleration forces) and their impact on the infant.</b>
	➤ <i>What are the adverse effects on babies to exposures in the transport environment (such as noise and vibration forces) and how can these be reduced?</i>
10	<b>Mental health issues and additional burden on families of transported infants.</b>
	➤ <i>What are the additional burdens on families of transported babies (such as mental wellbeing) and how can these best be supported?</i>

**Table 8. Final Top 10 Research Priorities for neonatal transport with research questions that could be asked within each priority.**



## Key points feedback from the facilitator from the group discussions:

### *Facilitator 1*

- Discussions were impressively thoughtful with contributors listening carefully and responding constructively.
- Parents' contributions were frequently excellent. The best example of this was related to topics concerned with parental mental health, where the knowledgeable delivery of personal experiences clearly helped clinicians understand where there are topics of transport-relevant interest that are amenable to structured evaluation. The willingness of the clinicians to listen carefully and adapt their views was also impressive.
- There was also evidence of parents' minds being changed by clinician views, for example around the topic of equipment failure during transport. Parents had rated this highly before the meeting, but the discussion revealed that this was because the topic sounded alarming and therefore important. Clinicians explained that in practice equipment breakdown is a very limited problem, partly because equipment is very reliable and partly because teams are thoroughly drilled in how to respond and have back-up plans.

### *Facilitator 2*

- There was a difference between the morning and afternoon groups in terms of how much appreciation there was of other people's perspectives. In the morning everyone listened to each other and whilst there were differences of opinion, there were a couple of light bulb moments where participants were suddenly aware of other perspectives that they hadn't thought about. The dynamic in the afternoon was less cohesive and there were quite a lot of conflicts about priorities and where they should sit. This may be because of the change of group participants or because we were further through the process and so individuals were fighting harder to get their personal priorities in the top ten.
- There was a split between parents and clinical staff for some priorities, the most obvious being the mental health and support of families. The parents/parents' representative in the group wanted this to be near the top of the list whereas the clinical staff felt it should be lower down because the transport period is only a small part of the whole neonatal journey and mental health support should be part of the whole neonatal care package.
- There was strong feeling that there should be an explanation of why priorities ended up in a particular position. For example, priority (H) (transfer of mums prior to birth) was thought to be slightly out of the remit of the exercise and therefore moved down the list even though it is an important issue.
- There were some priorities which morphed into something slightly different. When we were talking about benchmarking priority (C) there was disagreement about what this meant and whether it was more about service provision or care of the baby/family. A comment was made that whilst care in individual centres and on the transfer was excellent, the communication between the different components of care was lacking. If benchmarking was going to address this then the priority would have been ranked higher than if it was about service provision/funding.

- The online format worked really well for the breakout groups as it was easier to keep to time and there was no opportunity for people to talk over each other or have cross-conversations.
- The organization behind the scenes and tech support made it such a success.

### *Facilitator 3*

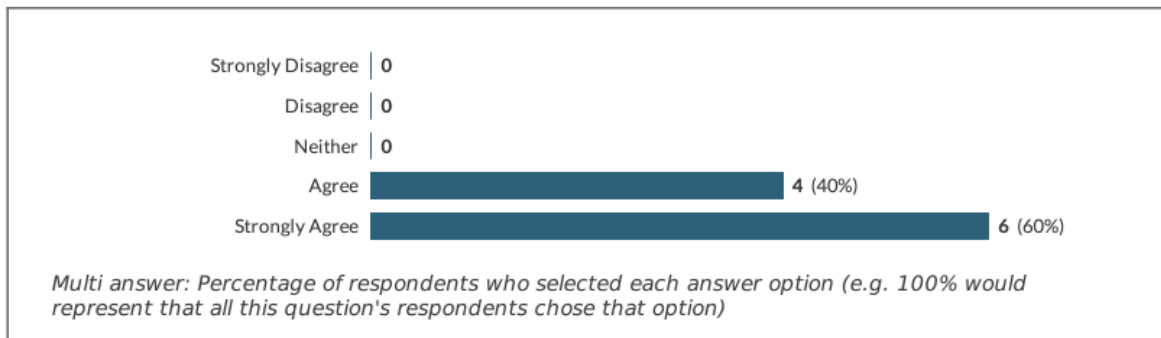
- It was evident people were more opinionated in the afternoon. People were trying to express strongly what was agreed in their previous breakout discussion groups. I think that was why it was harder to agree on an order in the third breakout session.
- There were differences in opinion between parents and clinical staff for some priorities. Some patients said that they did not choose certain options because they did not understand why they might be important.
- From the first two breakout sessions, healthcare professionals were particularly agreeing that In Utero Transport (H) was important. Some parents were more in favourable of other issues such as environmental factors e.g. the effect of vibration (L) and noise (J) and the restraining device (F).
- From the first two breakout sessions, (E) (Dealing with death and bereavement) and I (Family support away from home) got the least votes overall. (E) was chosen because it is such a rare event, and (I) was chosen because it falls out of the remit for Transport research.
- Some clinical staff also did not choose certain options because they were aware of research already being done in that area. For example, someone said that the impact of vibration and noise exposure was already being explored. This did lead to differences in opinion as some people were not aware of this research.
- There was also discussion as to what would be included with certain research priorities e.g. the benchmarking system (C) as it wasn't clear. People also thought the 'risks' priority (N) was too broad and needed defining better. It was also agreed that equipment failure (S) would be included as a risk.
- In the third breakout session, there were a few individuals from the same group previously that could not understand why invasive and non-invasive ventilation (M and V) priorities were in the top ranking from the overall group.
- In Utero transport (H) was the top ranked priority from the first two breakout sessions in my group, it was surprising that this did not get a high ranking overall. Someone from the third breakout session said that this should be done separately as it would be a big piece of work.

**Post workshop feedback:** 10 responses out of the 18 delegates that attended (6 HCP 4

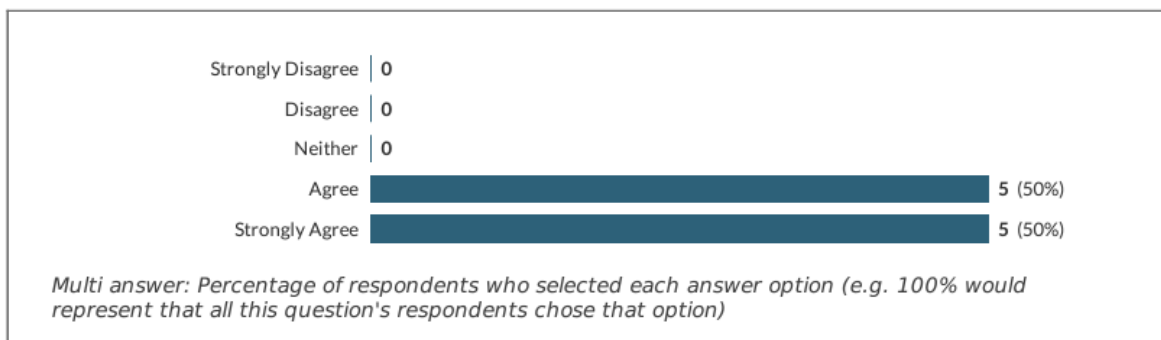
Parents) Results of responses listed below

**1** To what extent do you agree or disagree with the following statements in relation to inclusivity and expressing your views during the workshop.

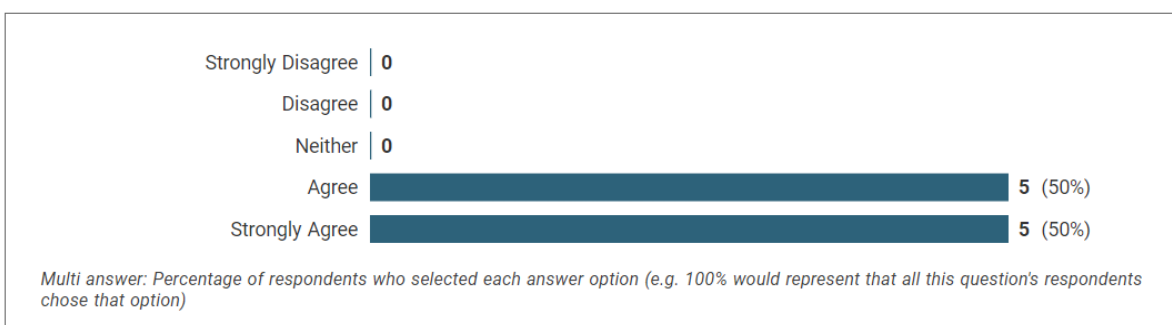
**1.1** I had equal opportunity to share my views throughout the workshop



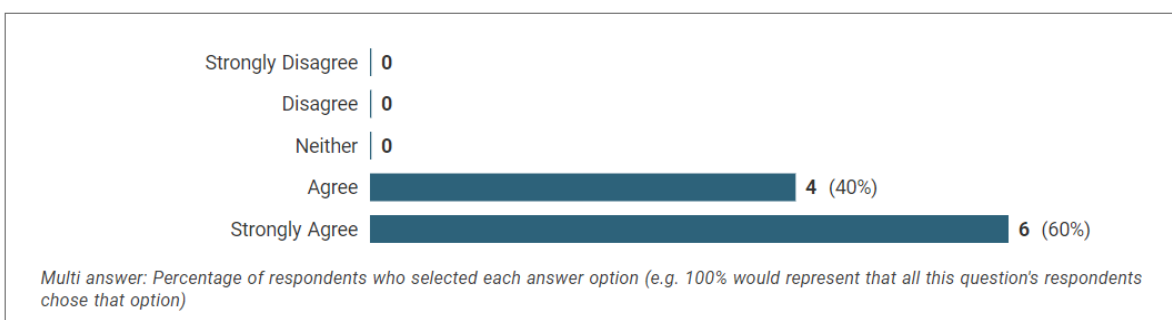
**1.2** I felt my views were heard in the group sessions



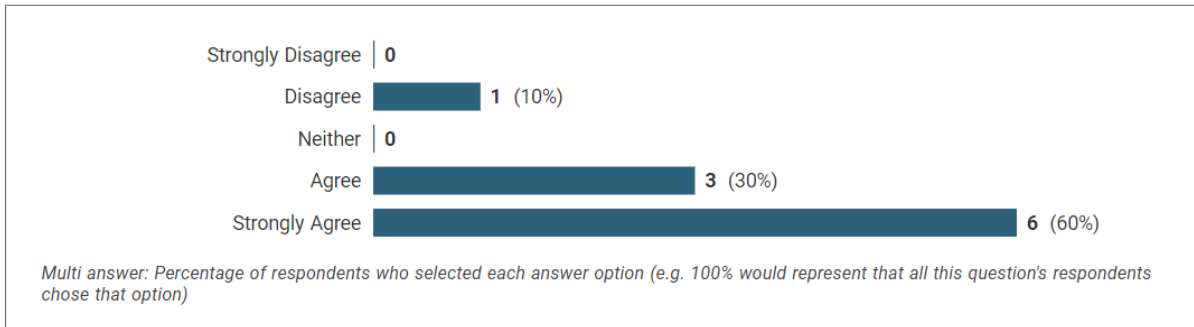
**1.3** The facilitators ensured everyone was included in the group sessions



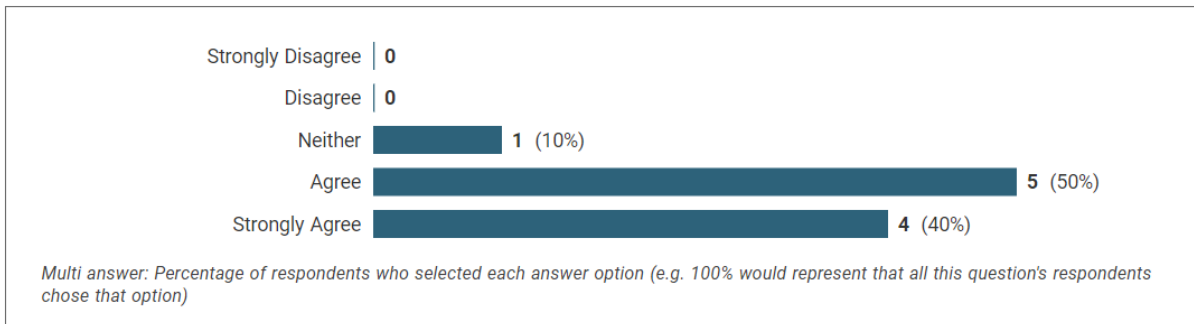
**1.4** I felt my views were respected by facilitators during the group sessions



1.5 I felt included with all aspects of the group sessions

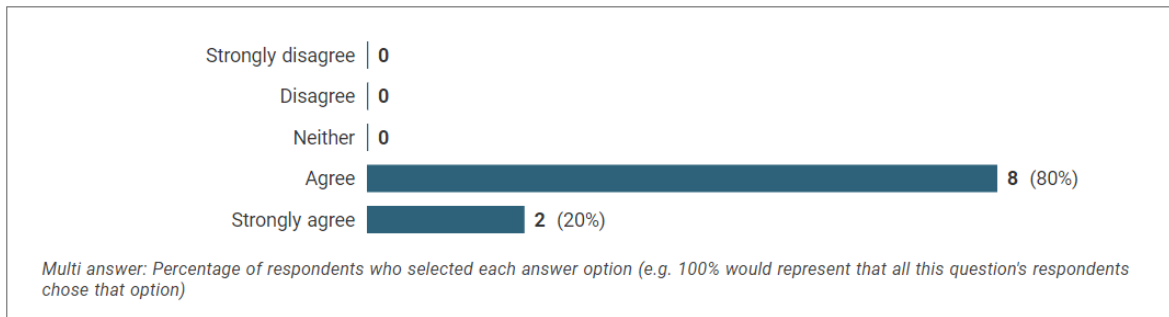


1.6 I felt included and able to voice my views in the plenary sessions.

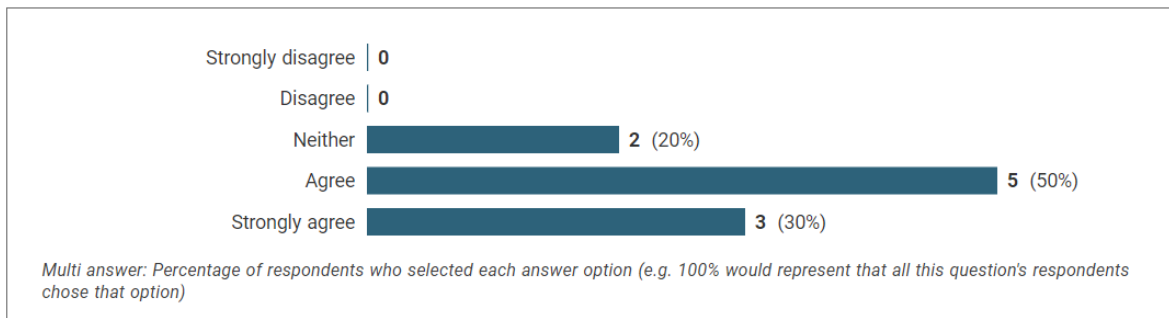


2 To what extent do you agree or disagree with the statements regarding the pre-workshop information?

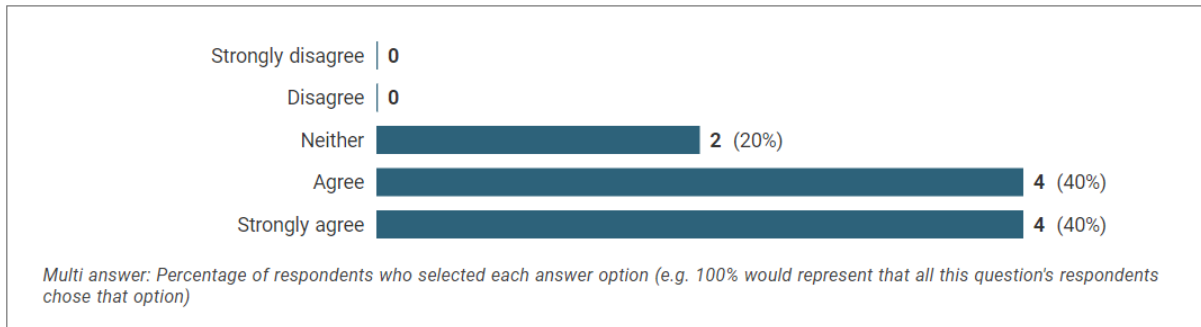
2.1 I felt well informed about the workshop with the information provided



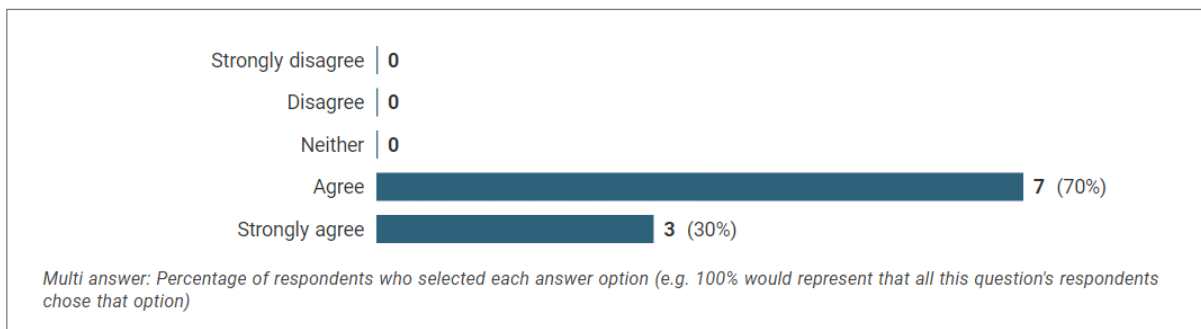
2.2 Research team responded promptly to any queries



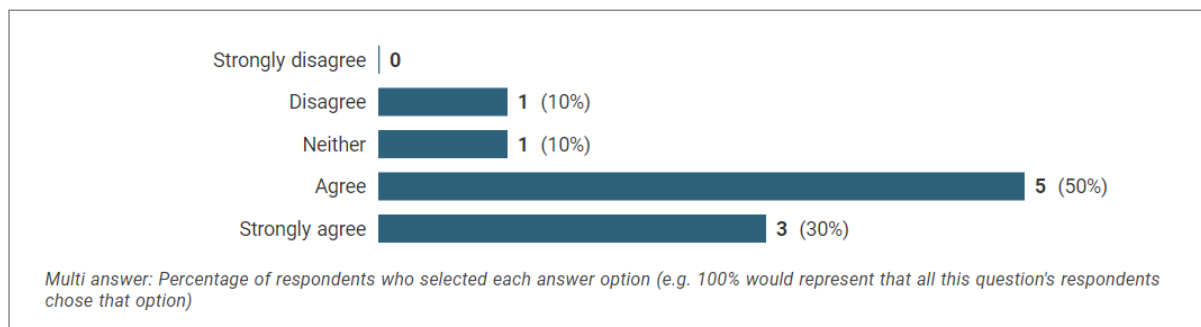
2.3 The registration process was easy to use



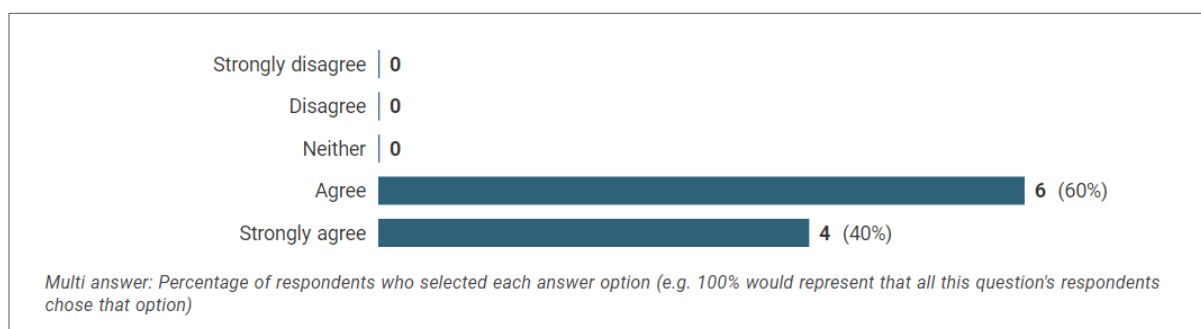
2.4 The pre-workshop material helped prepare for the workshop



2.5 The pre-workshop material was clear and concise

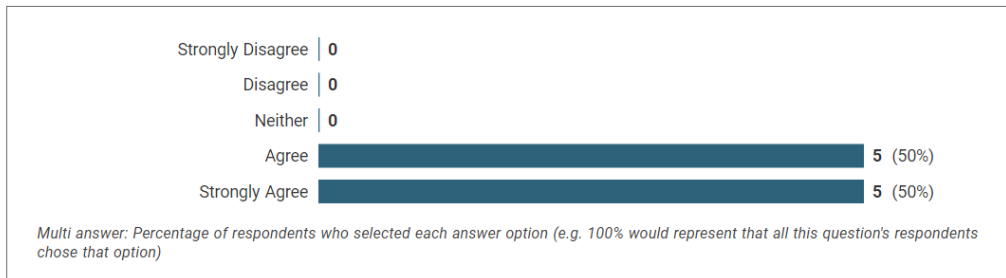


2.6 I was given enough time to complete the pre-workshop exercise

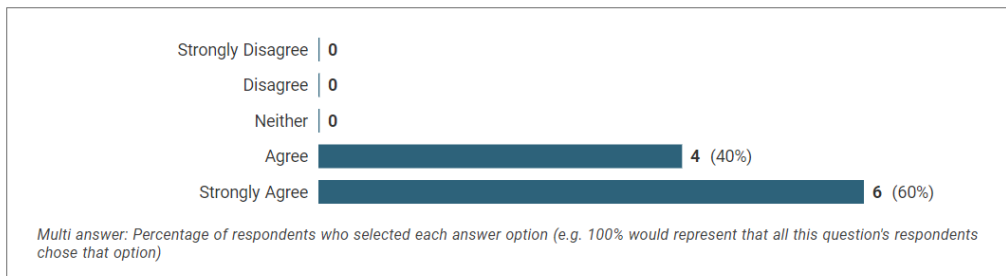


3 To what extent do you agree or disagree with the following statements about the technology (MS Teams) and the online format of the Neonatal Transport workshop?

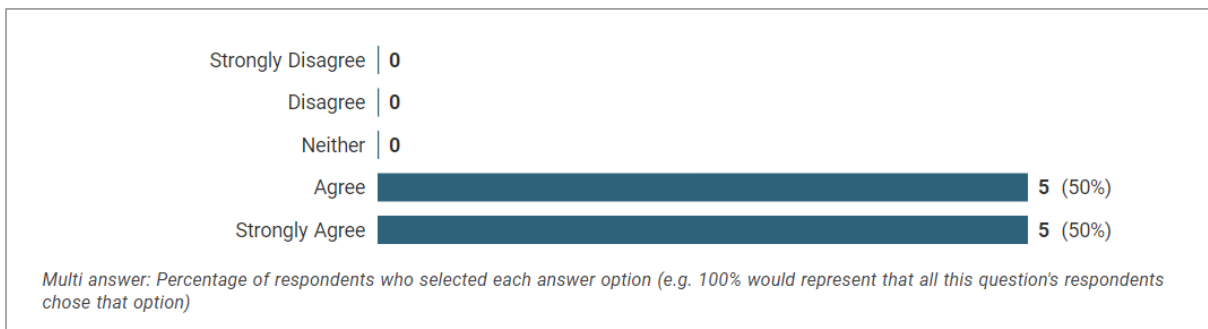
3.1 The technology was easy to use



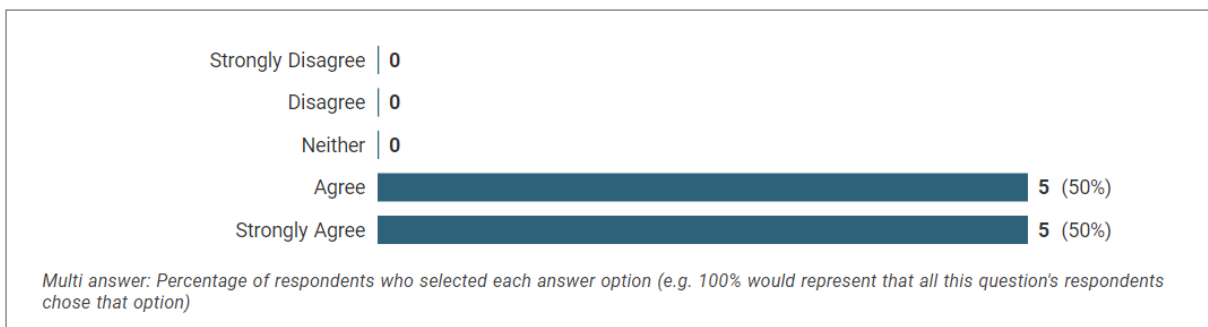
3.2 I could follow what was happening during the workshop



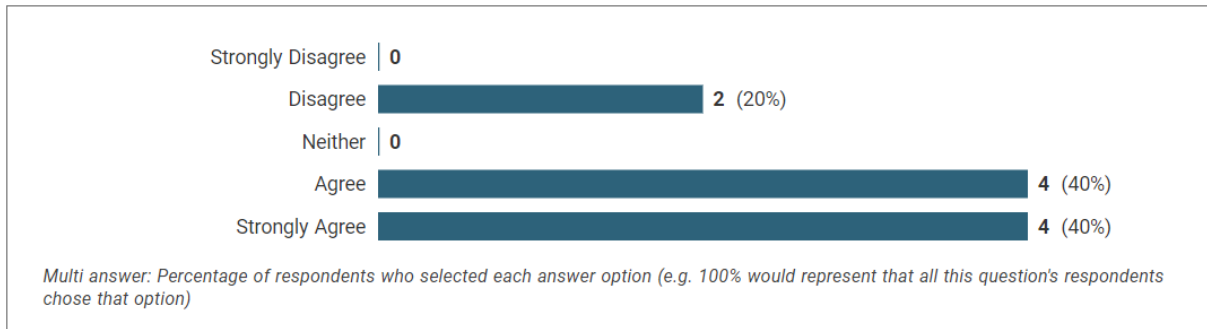
3.3 I was able to interact with the facilitators



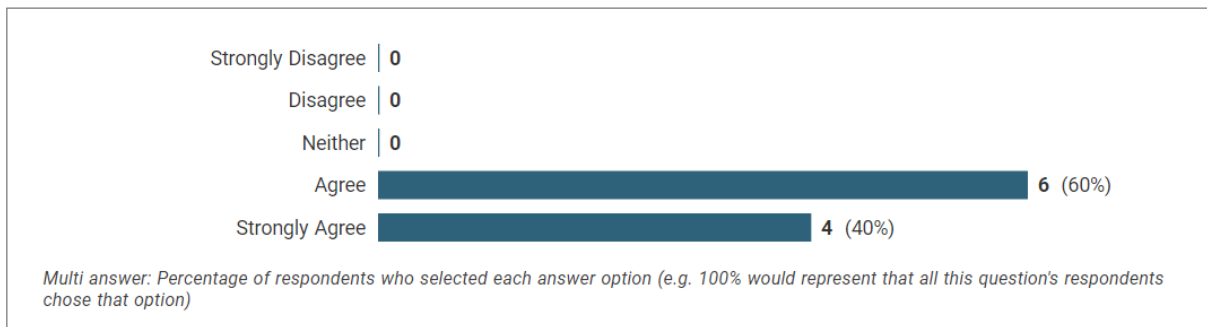
3.4 I was able to interact with other participants during the group sessions



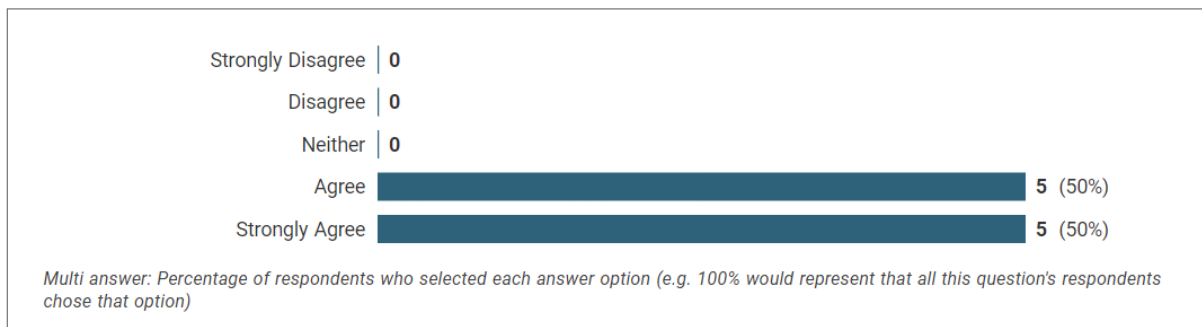
3.5 The length of the workshop was appropriate



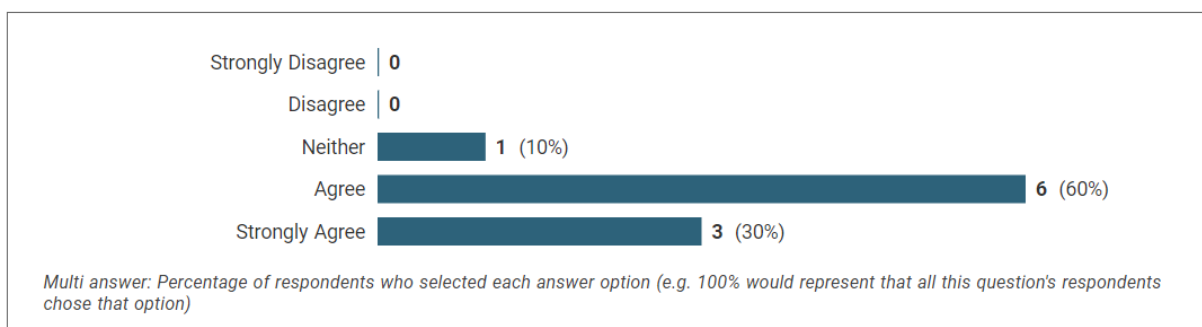
3.6 There were enough breaks



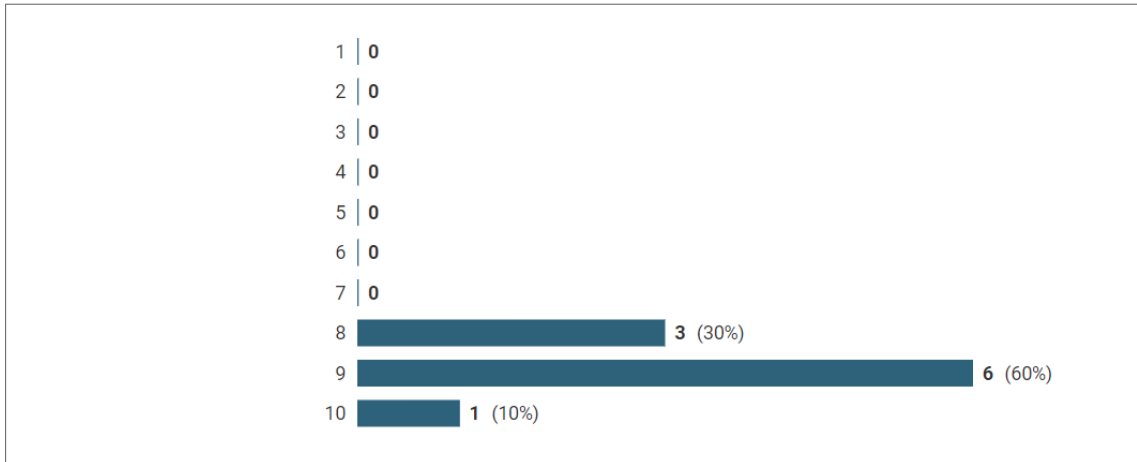
3.7 I had no problems connecting and participating via MS Teams



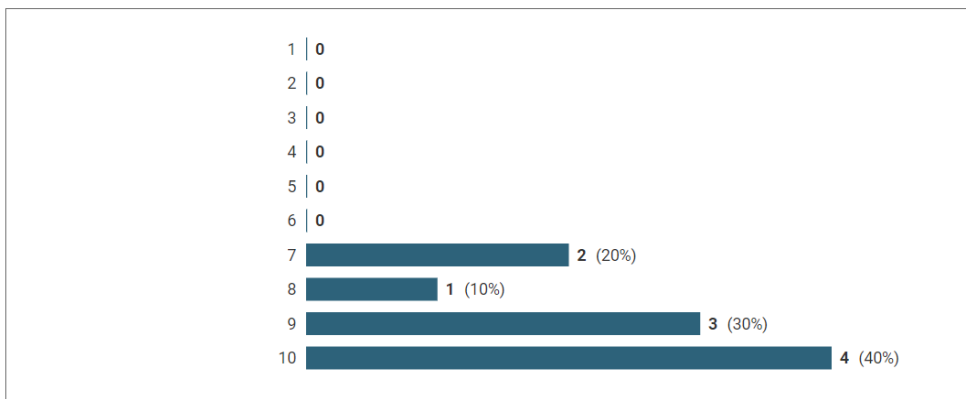
3.8 The padlet screen used to visualise the research priorities was helpful



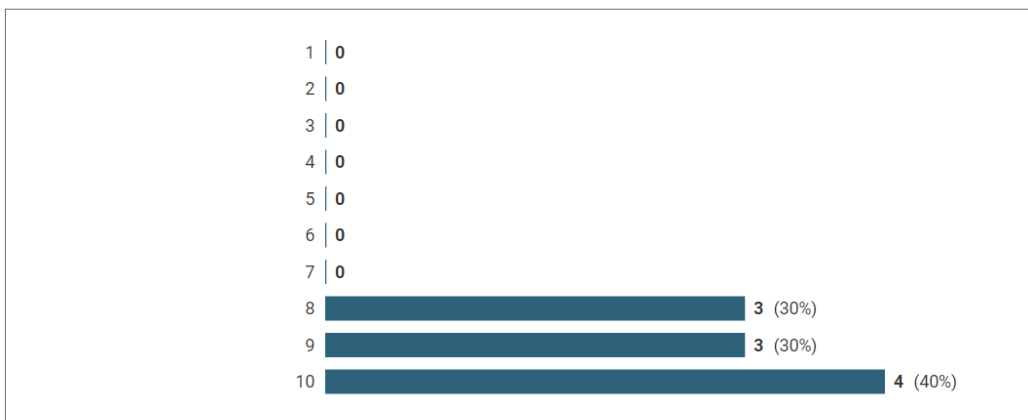
4 How would you rate the overall running of the workshop? Please give a score out of 10, (1 being the lowest and 10 being the highest) .



4.b How would you rate the delivery of the opening presentations of the workshop? Please give a score out of 10, (1 being the lowest and 10 being the highest) .

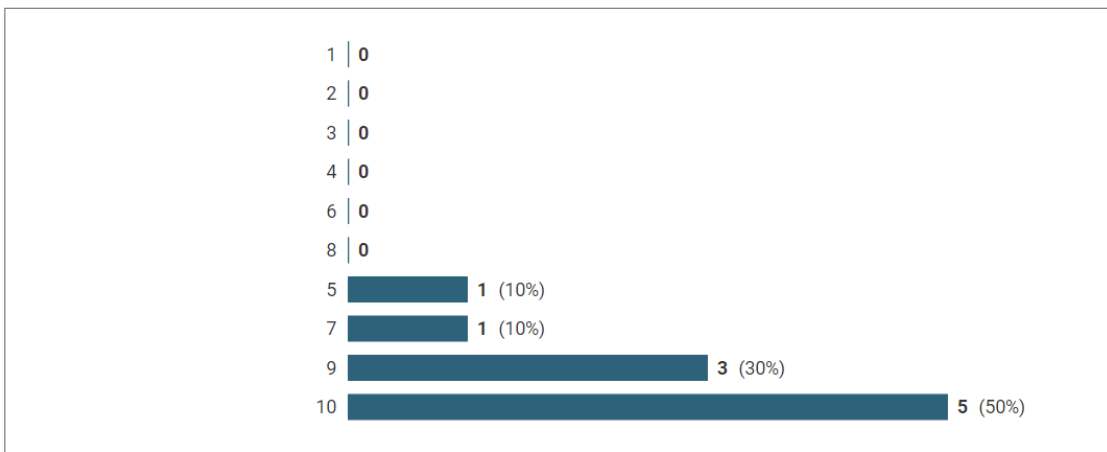


4.c How would you rate the chairing of the plenary discussion session? Please give a score out of 10 , (1 being the lowest and 10 being the highest) .

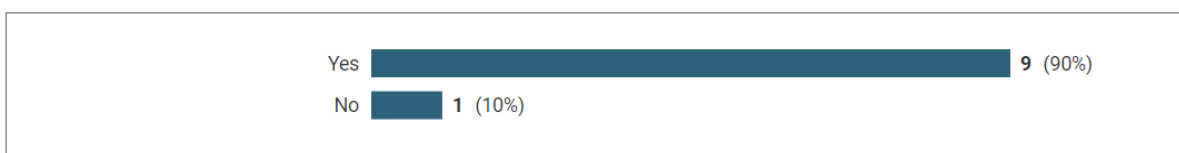




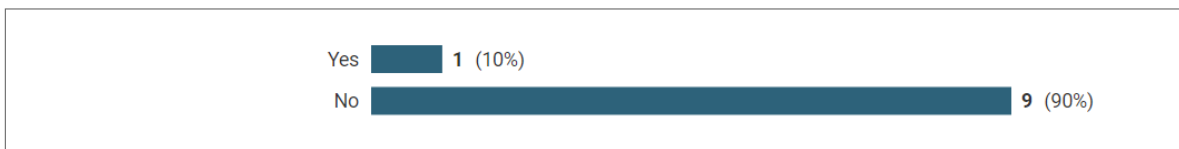
4.d How would you rate the facilitators in your group sessions? Please give score out of 10 (1 being the lowest and 10 being the highest)



5 Would you prefer future workshops to be run virtually?



5.b Would you prefer future workshop to run face to face?



### Overall feedback comments

- Well organised and facilitated.
- I thought the facilitators in the group stages was excellent.
- I thought this was excellent!
- Well, led meeting thanks
- Think it might've been helpful to have a sense of what might be done with the output. Also, some were not clear if we were scoring on the potential to be a feasible research or whether it was an exercise in prioritizing topic areas.
- It was hard initially working off the statements with no context.
- Well organised and run.
- Run exceptionally well, really enjoyed the process
- Morning into groups was quick. If it had been outside of working hours you may have got a more diverse set of participants.
- Timing of meeting would have been better if finished before school pick up, in terms of parent commitments.
- Thoroughly enjoyed the session with input from professionals and parents
- The padlet screen as an idea is great but the limitations applied by showing it through teams meant that it was small and so one could not visualise all the priorities on one screen.
- The chairing was clear and well done in terms of allowing those who wished to say things to have their say.

## References

1. Jisc online surveys [Available from: <https://www.onlinesurveys.ac.uk/>.] Accessed January 2024
2. JLA Guidebook | James Lind Alliance [Available from: <https://www.jla.nihr.ac.uk/jla-guidebook/>.] Accessed January 2024