

TITLE PAGE

Research priorities for UK paediatric critical care in 2019: Healthcare professionals' and parents' perspectives

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Article tweet: Parents and PICU healthcare professionals research priorities for critically ill children identified

Declaration of potential conflicts

Dr Lyvonne Tume was an expert member and deputy vice chair of the National Institute for Health Research (NIHR) Health Technology Assessment Maternal, Women's and Child Health topic identification panel during the time this exercise was conducted.

Dr Julie Menzies is a NIHR Senior Nurse and Midwife Research Leader and Dr Barnaby Scholefield is a NIHR funded Clinician Scientist. Dr Samiran Ray did not receive any direct funding but was supported by the NIHR Great Ormond Street Hospital Biomedical Research Centre. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.

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ABSTRACT

Objective: The Paediatric Intensive Care Society Study Group conducted a research prioritization exercise with the aim to identify and agree research priorities in Pediatric Critical Care in the United Kingdom (UK) both from a healthcare professional (HCP) and parent/caregiver perspective.

Design: A modified three round e-Delphi survey, followed by a survey of parents of the top 20 HCP priorities

Setting: UK PICUs

Population: UK Pediatric Intensive Care Unit (PICU) HCP who are members of the professional society and parents and family members of children, with experience of a UK PICU admission

Interventions: None

Main outcome measures: A list of HCP and parent research priorities for PICU in the UK.

Results: Forty-nine HCP submitted topics in round one, 98 participated in round two and 102 in round three. These topics were categorized into eight broad domain areas, and within these there were 73 specific topics in round two. At round three, 18 topics had a mean score < 5.5 and were removed, leaving 55 topics for ranking in round three. Ninety-five parents and family members completed the surveys from at least 17 UK PICUs. Both parents and HCP prioritized research topics associated with the PICU workforce. HCP research priorities reflected issues which impacted on day to day management and practice. Parents' prioritized research addressing acute situations such as infection identification of and sepsis management, or research addressing long term outcomes for children and parents after critical illness. Parents prioritized research into longer term outcomes more than HCP. Parental responses showed clear support for the concept of research in PICU, but few novel research questions were proposed.

Conclusion: This is the first research prioritization exercise within UK PICU setting to include parents and families' perspectives and compare these to HCP. Results will guide both funders and future researchers.

INTRODUCTION

High quality evidence is vital for care provision within pediatric intensive care, where decision-making impacts most acutely on morbidity and mortality [1]. However, a scoping review of randomised controlled trials in the PICU setting [2] highlighted the lack of evidence surrounding many aspects of care provision and the need for trials with rigorous methodology and appropriate outcome measures. In planning research, it is vital to prioritize resources in the most relevant areas bringing together the views of patients, carers, and clinicians. In the UK, organisations such as the James Lind Alliance) have created such Priority Setting Partnerships) to systematically identify and prioritize the top 10 unanswered questions around a particular health condition or patient population. No such exercise has been undertaken for pediatric critical care [3,4]. The Paediatric Intensive Care Society Study Group is a multi-disciplinary special interest group of the society [5]. The group's vision is to improve the care of critically ill children through the conduct of high quality, multi-centre research studies within United Kingdom and the Republic of Ireland. In order to establish a research agenda and ensure that high priority research was being addressed, a research prioritization exercise was conducted with the aim to identify and agree research priorities in pediatric intensive care in the UK both from a healthcare professional (HCP) and parent/caregiver perspective.

METHODS

Health Care Professionals

We undertook a modified three round e-Delphi study to generate consensus around PICU HCP priority research areas between April and June 2018. This approach is a well establish method to generate research priorities [6]. It uses a series of structured questionnaires (rounds) to reach consensus, the level of which is predefined [7]. Round one is an open-ended questionnaire to ask participants to list research topics, this round is analysed qualitatively, and topics categorized into themes and duplicates removed. These topics are then distributed to the whole group for ranking on a Likert scale in terms of perceived importance and priority, with items below a pre-defined level removed from the final round. Round three asks participants to re-rank the remaining items considering the group mean score (which is provided) to reach 'consensus' [6].

The e-survey was sent to all UK Paediatric Intensive Care Society members (n=654). Members of this group include any healthcare professional working in the field of pediatric intensive care. The survey collected demographic variables

of the participants, and optional participant emails so we could clarify any topics submitted that were unclear and to reduce attrition rate through the survey rounds.

Round one asked participants to submit a maximum of three research topics, these were analysed independently and categorized qualitatively by (LT/SR) with any discrepancies resolved through discussion. These were then developed into a survey for Round two, with a 0-10 Likert scale for participants to rank the items in terms of perceived importance and research priority. We also added three additional 'new' non-duplicate topics that were generated from the 2017 study group meeting using an informal research prioritization approach. We defined a priori items with a mean score of <5.0 (on a 0-10 Likert scale) as not achieving consensus but adjusted this to <5.5 considering the high ranking of all topics in round 2 (all topics mean score 5.8). These items would be removed from round three. The highest scoring topics was sent back to the participants in round three with the group mean score beside the topic, for participants to re-rank in terms of priority (considering the group score), generating a final list of top research priorities. After each survey, three reminders were sent a week apart, to increase response rates across the three surveys. Time between rounds was six weeks to reduce attrition.

Parent and family engagement

Parents and families of children who had an admission to PICU in the UK or Republic of Ireland, were invited to complete a survey. This invitation was done through multiple methods. No restriction was placed on when the admission had occurred, the child's survival or their age.

Recruitment method 1: All PICU nurse managers were contacted and their PICU asked to participate. Responding sites were contacted individually to establish a point of contact and postal address and then provided with a pack of 25 questionnaires / site, postage paid envelopes and posters to help raise awareness of the work. In addition, a QR code with link to an electronic version of the survey was also made available for parents. The survey was distributed over a two-month period (October – December 2019). Response rates were not monitored, and units were not asked to return unused questionnaires. Due to this method, the number of questionnaires distributed is reported, but response rates could not be calculated. Recruitment method 2: Children and family members also could access an electronic version of the survey through links on the society website and via social media. Recruitment method 3: Finally, three

charities disseminated the link to their members, The Child Brain Injury Trust, Little Heart Matters and Evelina Children's Heart Organisation.

A single English language version of the survey was developed for all participants. The top 20 questions/topics prioritised by HCP were used for the parent survey. Many of these questions were in a PICO (Patient, Intervention, Comparison, Outcome) format. To improve understandability, these questions were reduced to core themes or topics following several rounds of consultation with parents with experience of intensive care experience and those with no intensive care experience (parents in ward areas / or members of the public) (*Supplementary File 1 Parent survey*). Using guidance from the patient charity called INVOLVE [8] a survey was constructed that was suitable for the average UK reading age of 12 [8] and could be understood by families [9]. The survey used text accompanied by professionally developed illustrations, to ensure the material was understandable. Participants were asked to rank the importance of each topic using the same 10-point Likert scale, the same as the HCP (1 not important to 10 very important). Recognizing that there might be questions which people felt unable to answer, and a 'not applicable / not able to comment' option was provided. Participants also had the opportunity of using free text to suggest a research question or topic which they felt was important which was not covered in the list of 20 subjects, and to add free text comments they wanted to say about research in PICU.

Data analysis

The surveys were conducted through SurveyMonkey (SurveyMonkey, CA, USA). Survey data was imported to a CSV file, were manually validated and cleaned in Microsoft Excel (Microsoft Corps, WA, USA) and exported into IBM SPSS v 25 (IBM, NY, USA) for further analysis. For the Delphi, means and standard deviations of rounds two and three were calculated and in the final round items were ranked on priority by highest mean and standard deviation score. Data from the parent surveys were manually entered into Microsoft Excel. Mean and standard deviation scores of the parent responses were also calculated. Mean scores were used to rank the items in terms of priority for HCP and parents separately. Free text responses and comments from the parent responses were reviewed independently by two of the authors (JM/BS) and analyzed by simple thematic analysis. These were then compared to the questions/topic areas generated by the HCP to review similarities and differences and novel questions/topics areas were highlighted.

Ethics

The HCP Delphi survey was, categorized according to the UK Health Research Authority, as staff research and did not require formal ethical approval [10]. It was, however, formally approved by the Pediatric Intensive Care Society Study Group who sent this out to the members of the society. For the parents and families, the survey was classed as 'patient engagement' [11] and did not require UK National Health Service ethical approval. Like the HCP survey, consent was implied by the return of the survey. The society's study group also approved the patient and public engagement work with families and the public.

RESULTS

Health Care Professionals

Forty-nine PICU healthcare professionals' submitted topics in round one, 98 participated in round two and 102 in round three (**Figure 1**). At round three, most (65%) respondents were physicians, with 25% nurses and the remainder allied health professionals (pharmacists 4.9%, dieticians 1.9%, physiotherapists 2.9% and psychologists 0.9%). We reviewed any missing items that were identified from the 2017 study group meeting topic identification exercise (three extra items were added): the creation of a national PICU parent and child involvement database for researchers, short and longer-term physical, cognitive, functional and psychosocial outcomes of children after critical illness and targeted interventions to retain staff working in PICU. These were all categorized into eight domain areas with 73 specific research topics in the categories below.

- Respiratory: 14 topics
- Neurological, sedation and delirium: 7 topics
- Cardiac and cardiac surgical intensive care: 9 topics
- Gut and nutrition: 4 topics
- Renal, fluids and blood products: 7 topics
- Sepsis and shock: 8 topics
- Impact of PICU on the child, family and staff: 10 topics
- Safety, quality, service improvement and outcomes: 13 topics

In round two, three items had a mean score >7.0 and were the highest rated topics. Eighteen topics had a mean score of <5.5 and were removed from round three, leaving 55 topics for ranking. The top twenty scoring items with the highest mean score (**Supplementary File 2**) were rated as the highest priority topics. All the remaining research topics are presented in **Supplementary File 3** under their domain category.

Parents and families

Twenty-eight PICUs were contacted and 19 responded with an expression of interest and were sent survey packs. Two sites reported not receiving the packs, therefore 17 PICUs from across the UK participated (425 questionnaires distributed to 17 centres). Ninety-seven responses were received. Eighty-six percent of respondents were parents/carers, 6% were family members and their ages ranged from 18-46 years. Due to the low number of responses from children (n=2) these were excluded from analysis. Fifty-six participants identified the PICU their child had been admitted to, which represented 17 different PICUs. Overall, parent respondents ranked all the research questions HCP had identified as important, with mean scores ranging from 7.43/10 – 9.04/10 and scored all the topics higher than the PICU HCP (**Supplementary File 2** and **Supplementary File 4**) with a wider range of scores for HCP.

HCP and parent response comparison

Comparing the top five highest scores for HCP and parents revealed that both groups rated research questions relating to PICU staff as the most important questions to address. Preventing PICU staff burnout was the highest priority for HCP and second highest for parents, with staff retention the third highest scoring for parents and fifth for HCP. This was reflected in the following quote from a parent:

“As a vital part of pediatric care, I hope research helps in recruitment and retention of staff in this area. The work they do is very hard, but amazing and life-saving.” [Parent].

The value of the intensive care workforce was also recognized, with research into Registered Nurse staffing ratios rated within the top ten scoring questions: sixth highest scoring for parents and tenth for HCP. Other similarities in the top ten were the importance of research into decision-making around end of life care (highest scoring item for parents compared with sixth for HCP) and research into targeted oxygen saturations (third highest for HCP compared with 10th for parents).

The two groups differed in several areas. Long term child outcomes and parental support following a PICU admission were the fifth and eighth highest items for parents. In contrast, they ranked 11th and 19th in the HCP priority. Free text comments from parents highlighted concerns about the care and support of the child after a PICU admission.

“I feel more support and research in to after care for long term patients would be a great benefit” [parent]. Parents also highlighted that research was needed to explore the needs of the whole family unit:

“Consideration of the Impact of a long term PICU stay on siblings and parents is important.” [Parent]

Differences between the groups’ views on more specific elements of medical care were evident in the scoring of topics related to intravenous fluid and sedation selection and management (**Supplementary File 2**). Despite lower scores for sedation management some parents expressed concerns about neurodevelopment and medications

“The quality of the baby’s brain performance capabilities after they have been sedated in an induced coma for over 2 weeks” [Parent]

“The effects of the paralysis drug during sedation on young infant, toddlers and babies” [Parent]

Parent research suggestions

Most parents (74/97, 76%) did not suggest additional research questions. However, of the 23 (24%) who did, there were 25 research topic suggestions (**Supplementary File 5**). Three reflected general support for research in PICU, rather than a specific question. The remaining 20 questions are listed in Supplementary file 3. Thematic analysis of parental suggestions reflected three key themes: research to explore the short and long term impact of PICU for the child and young person, care and support for parents and families on and after PICU, and PICU staffing and care planning. Only one question did not relate to the HCP research priorities, and this concerned designing improved fit non-invasive ventilation hats for infants.

DISCUSSION

In the UK, no formal prioritization of pediatric intensive care research topic has been conducted before. To our knowledge, this is the first study to examine and compare healthcare professionals and children and family views around research priorities in pediatric intensive care. Research priorities have however, previously been studied in

pediatric [12] and neonatal intensive care nursing [13] across Europe and Australia [14] and in other fields of pediatric medicine [15,16], but few of these explored priorities from a multi-professional lens and explored parental priorities.

Both HCPs and parents highlighted the need for research into staff retention and prevention of burnout. It is possible that the context of PICU in the UK in 2018 will have influenced these priorities for both HCP and parents, as may a concurrently run, society-led staff survey of post-traumatic stress disorder and burnout [17]. The prioritization of research to reduce staff stress, along with topics to improve staff retention, reflects a growing staffing crisis within the specialty. Parents and families also recognised that stress and burnout was an issue in PICU staff, and they prioritized the topic of interventions to retain staff. Despite both participant groups recognising the important of research to address staff wellbeing or staff retention, there are currently no national studies in progress addressing these topics.

Many of the research questions scored highly by HCPs included interventions around respiratory support, fluid, blood pressure and sedation management. Several studies, either feasibility or full trials, are underway in the UK to test these or related questions. Trials to explore oxygen target thresholds in ventilated children (OXY-PICU) [18], comparing high flow nasal cannulae to non-invasive respiratory support (FIRST-ABC)[19], standardized sedation targets and weaning from the ventilator (SANDWICH)[20], fluid regimes for resuscitation (FISH)[21] and blood pressure targets in PICU (PRESSURE)[22] have all been funded by the UK National Institute for Health Research.

Interestingly, the parent group scored the topic of decision making around end-of-life for children admitted to PICU as the highest priority area for research (ranked 6th by HCPs). In both the US and the UK, the most common location of pediatric death is the PICU [23-24]. Many of these deaths involve withdrawal of one or more forms of life-sustaining medical treatment, therefore discussions around end of life care and decision-making are clearly important both for families as well as HCP. Currently, no studies are investigating this issue within the UK; however, a recent study of end of life care across PICUs in Switzerland has just been published [25].

With 96% of children surviving critical illness in the UK [26], understanding the longer-term impact for children and their families was not surprisingly identified as more important by parents. Currently only one UK study, [OCEANIC 27], is studying the longer-term impact on the child and family of critical illness. Consistent with optimising the outcomes of survivors of critical illness, interventions aimed at enhancing the child and family outcomes were also viewed as important. Of note, some parents expressed concerns between neurodevelopmental outcomes and

sedation drugs, yet only three research questions around sedation were prioritized by the HCPs. The NIHR-funded Sedation and Weaning in Children (SANDWICH) trial results are imminent [20] Additionally, another UK feasibility study of early mobilization and rehabilitation (PERMIT study) is under way [28].

Several research questions prioritized through this process could be merged to make research delivery more efficient. Quality Improvement (QI) initiatives may help this process, particularly around interventions looking to improve staff retention and reduce burnout. Adaptive platform trials can study multiple interventions simultaneously. Randomisation to several interventions can occur simultaneously or in predefined stages, adapted based on the ongoing analysis of results. The ongoing NIHR-funded RECOVERY trial for COVID-19 therapies (ClinicalTrials.gov Identifier: NCT04381936), and the ambitious REMAP-CAP trial (ClinicalTrials.gov Identifier: NCT02735707) for treatment of community acquired pneumonia in adults offer examples of such trial designs. Such platform trials could be designed for related topic areas, for example, blood pressure targets, inotrope choice and use of steroids in sepsis, or could be used to answer several broader questions around treatment strategies: use of oxygen, inotropes, fluids and sedation for instance. Furthermore, embedded trials could harness knowledge gained from every child admitted to PICU, allowing treatment strategies to be tested in different disease categories for example, children following unplanned admission or cardiac surgery.

A similar prioritization exercise was undertaken in adult critical care in the UK in partnership with the James Lind Alliance [4]. In contrast to our methods, this process involved a formal partnership between patients, carers and HCPs to identify uncertainties in clinical care and prioritize research into these areas, through a process of surveys and workshops. Four of the adult critical care top 10 priorities are reflected in our top 20: longer term outcomes after critical illness, identifying and managing delirium, decision-making around end of life and earlier mobilization and rehabilitation. The differences may reflect the differences in our methodology, but also the differences in adult and paediatric critical care including the larger burden of uncertainty in pediatrics.

There are several limitations of this study that warrant highlighting. One important point is that this work may not be generalizable outside the UK context. Any research prioritization exercise is highly associated with the context and time point at which it is undertaken, and some potential societal and high profile cases in the media at the time this was undertaken that may have influenced our findings. Despite a current paediatric intensive care society membership of 654, only 49 individuals suggested research topics in round one. This may be because many clinicians

were not confident in the development and wording of research questions. However, more voted in rounds two and three, suggesting they had views around research priorities. Three quarters of the respondents were physicians, which will have influenced topics suggested. Unlike the similar adult ICU exercise, parent involvement in our study occurred only after the top 20 research topics were identified by HCPs [4]. This may have limited the potential for parents to introduce new areas of research because of not being presented with a blank sheet. However, parents were able to suggest new topics but only a quarter did. A further limitation was that the survey was only available in English and we did not assess for respondent understanding of the questions/topics. However, there is no single national parent and child charity or support group for PICU to assist with engagement with current and former service users [29]. To overcome this, we tried to be inclusive in offering all PICUs the opportunity take part, inclusive in different approaches to participation and inclusive in who could participate; and our participant demographics demonstrate we achieved this. The inclusive approach could, however, have led to completion of the questionnaire by individuals without experience of a child being admitted to a PICU. The formal PICO nature of the HCP questions had to be significantly reduced to topics and themes to make the work more accessible to parents and families. This may have changed the meaning of the HCP topics and may affect their translation into practice. Despite these limitations, this is the largest formal study to prioritize UK PICU research topics from a multi-professional perspective and involving parents and caregivers.

CONCLUSIONS

The views of HCP and families surrounding research priorities in PICU across UK have been explored and prioritised. These results are vital to guide clinicians, researchers and funding organisations in addressing studies of the highest importance and impact. Overall, parents supported the prioritised HCP research areas, particularly including research into staff wellbeing and staff retention. Greater emphasis on research into longer term outcomes in children after PICU was requested by parents. We believe the results of this research prioritization exercise will contribute to more relevant HCP and parent UK research, with increasing efforts to focus on clinical priorities that are likely to lead to improvements in the care and management of critically ill children and young people.

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Figure Legends:

Figure 1: Delphi Study Flowchart.

Supplementary File 1: Parent and families survey instrument

Supplementary File 2: Comparison of top 20 ranked health care professionals and corresponding parent priorities

Supplementary File 3: Full list of health care professional prioritised research topics

Supplementary File 4: Visual display of healthcare professional to parent ranked topics

Supplementary File 5: New questions raised by parents mapped to the HCP generated research questions

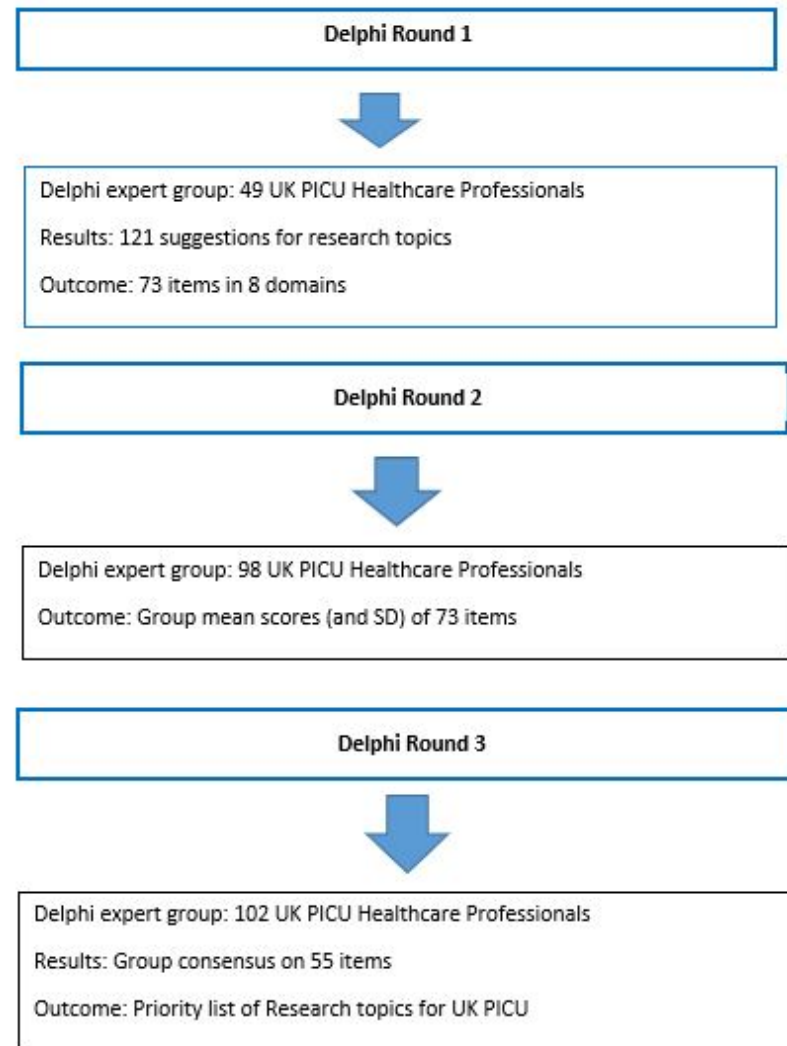
Supplementary File 2: Comparison of top 20 ranked health care professionals and corresponding parent ranking

HCP based rank	HCP ranked Topic	Mean (SD) score	Parent based rank	Corresponding parent ranked topic (lay language)	Mean (SD) score
1	In PICU staff, would targeted interventions to reduce staff distress, compared to nothing, impact on Post-Traumatic Stress Disorder (PTSD), burnout, retention rates and moral distress?	7.63 (1.7)	2	Interventions to prevent PICU staff stress/burnout	8.95 (1.6)
2	In ventilated children on sedation, does sedation cycling compared to no cycling impact on length of ventilation, PICU length of stay, accidental extubation, withdrawal and delirium?	7.30 (1.7)	13	Sedation medicine regime (cycling drugs)	8.25 (1.7)
3	In ventilated children requiring oxygen, does titrating the FiO2 to achieve Spo2 targets of 88-92%, compared to the standard target of >94% impact on length of ventilation and mortality?	7.29 (1.9)	10	Targeted oxygen saturations	8.40 (1.4)
4	In ventilated children, does the use of balanced crystalloids (Plasmalyte, Hartmann's) compared to dextrose/saline maintenance solutions, impact on acute kidney injury and metabolic acidosis?	7.23 (1.7)	20	Different type of fluids	7.43 (2.1)
5	In PICU staff, do targeted interventions to retain staff working in PICU, compare to standard practice, impact on staff retention rates	7.05 (1.7)	3	Interventions to retain PICU staff	8.94 (1.4)
6	What are parents' experiences of conversations about life limitation?	6.98 (1.9)	1	Decision-making around end of life care	9.04 (1.4)
7	All mechanically ventilated children, does nurse/physiotherapist-led ventilator weaning compared to standard doctor-led ventilator weaning impact on length of ventilation and length of stay?	6.89 (1.7)	16	Weaning the ventilator- health care professionals not just doctors	8.04 (2.0)
8	In ventilated children on PICU, would a more restrictive fluid intake (dry lung strategy) compared standard fluid allowance, impact on length of ventilation and mortality?	6.81 (1.5)	19	IV fluids allowance (more restrictive) in ventilated children	7.79 (1.8)

9	In children requiring sedation on PICU, does the use of IV dexmetomidine as the primary sedation drug, compared to standard sedatives, impact on length of stay, incidence of withdrawal and delirium?	6.80 (1.9)	18	Testing a new sedation medicine (dexmetomidine)	7.89 (1.9)
10	In ventilated children on PICU with single organ failure, does 1:2 RN: patient ratio, compared to standard 1:1 ratio, impact on adverse events, costs and length of ventilation?	6.75 (1.7)	6	PICU Nurse: Patient staffing on outcomes	8.50 (2.0)
11	What are the short and longer-term physical, cognitive, functional and psychosocial outcomes of children after critical illness?	6.70(1.8)	5	Long term outcomes of children after PICU	8.61 (1.7)
12	In PICU children on antibiotics for >48hours for suspected infection, does rapid pathogen identification and antibiotic rationalisation, compared standard practice, reduce the prevalence of antibiotic resistance and improve cost-effectiveness?	6.68(1.9)	4	Use of quick tests for bacterial infection to stop IV antibiotics	8.84 (1.4)
13	In all children admitted to PICU, does a care bundle including screening for delirium and specific interventions, compared to standard care reduce length of stay, improve quality of life and improve neurological morbidity?	6.56 (1.8)	15	Identifying and treating confusion (delirium)	8.12 (1.7)
14	In PICU children with Traumatic Brain Injury (TBI) with seizures, is levetiracetam (Keppra) compared to phenytoin as effective in preventing post-traumatic seizures?	6.50 (1.7)	7	New drug (levetiracetam) for seizures after traumatic brain injury	8.48 (1.8)
15	In PICU children with sepsis on inotropic support, does the administration of IV steroids, compared to no steroids, impact on length of ventilation and length of stay and other outcomes?	6.48 (1.8)	14	Steroids in septic shock	8.25 (1.6)
16	In term neonates with single ventricle or those post-op with low cardiac output syndrome (LCOS), does non-nutritive (trophic) feeding, compared to full enteral feeding, impact on Necrotising Enterocolitis (NEC) and other outcomes?	6.45 (1.6)	12	Milk feed allowance in ill babies (trophic vs. full feeding)	8.33 (1.6)

17	In children on PICU with shock requiring inotropes, does the use of adrenaline infusion, compared to dopamine infusion, impact on mortality, length of ventilation, need for renal replacement therapy and time to shock resolution?	6.44 (1.6)	9	Comparison of medicines (inotropes) for blood pressure management (sepsis)	8.45 (1.6)
18	In children on PICU with blood pressure <50th centile (hypotension), does targeting therapy to maintain blood pressure >5th centile, compared to standard management which targets therapy to maintain blood pressure >50th centile, impact on the length of ventilation, organ dysfunction and mortality?	6.43 (1.8)	17	Blood pressure targets	7.95 (1.8)
19	In children ventilated more than 48hr, would a standardised parent support plan, compared to standard care, improve psychological and functional outcomes in children and families after PICU discharge?	6.39 (1.8)	8	Parental support plan after PICU	8.47 (1.9)
20	In critically ill children, does an early mobility intervention program, compared to no early mobility intervention, affect parental satisfaction perceived quality of life of their child, adverse events and staff satisfaction?	6.38 (1.6)	11	Does a PICU early mobility programme improve outcomes	8.3 (1.7)

Figure 1: Delphi Study Flowchart



Supplementary File 3: Full list of health care professional prioritised research topics in Round 2 and Round 3

Research domains and topics	Round Two score Mean (SD)	Round Three score Mean (SD)
Respiratory domain		
In ventilated children requiring oxygen, does titrating the FiO ₂ to achieve Spo ₂ targets of 88-92%, compared to the standard target of >94% impact on length of ventilation and mortality?	7.42 (2.7)	7.29 (1.9)
All mechanically ventilated children, does nurse/physiotherapist-led ventilator weaning compared to standard doctor-led ventilator weaning impact on length of ventilation and length of stay?	6.91 (4.4)	6.89 (1.7)
In intubated children < 8 years ventilated > 48 hours, do cuffed ETTs compared to uncuffed ETTs impact on upper airway obstruction/problems?	6.40 (2.2)	6.23 (1.7)
In children who are extubated on PICU requiring respiratory support post extubation, is CPAP better than humidified high flow nasal cannula support, with regard to rates of reintubation/length of stay?	6.10 (5.8)	6.22 (1.8)
In children with ARDS, does the use of an FiO ₂ /PEEP based algorithm (as per ARDSNet) compared to standard care, impact on the length of ventilation and other lung outcomes?	6.04 (2.7)	5.90 (1.7)
In children with a lower respiratory tract infection or asthma, does the use of endotracheal DNase as a mucolytic, compared to no use of DNase, impact on length of ventilator support?	6.03 (5.1)	5.84 (1.9)
In children with ARDS, does the use of an 8ml/kg target tidal volumes compared to the use of 6ml/kg target tidal volume, impact on the length of ventilation, need for advanced support and lung function at 6 months?	5.70 (5.1)	5.61 (1.8)

In all children needing emergency intubation, does the use of high flow nasal cannula oxygen for apnoeic oxygenation, compared to pre-oxygenation with a mask, impact on adverse intubation events?	5.87(6.8)	5.46 (1.8)
Neurological, Sedation and delirium domain topics		
In ventilated children on sedation, does sedation cycling compared to no cycling impact on length of ventilation, ICU length of stay, accidental extubation, withdrawal and delirium?	7.30 (4.1)	7.30 (1.7)
In children requiring sedation on PICU, does the use of IV dexmetomidine as the primary sedation drug, compared to standard sedatives, impact on length of stay, incidence of withdrawal and delirium?	6.94 (2.7)	6.80 (1.9)
In all children admitted to PICU, does a care bundle including screening for delirium and specific interventions, compared to standard care reduce length of stay, improve quality of life and improve neurological morbidity?	6.82 (3.3)	6.56 (1.8)
In PICU children with Traumatic Brain Injury (TBI) with seizures, is Levetiracetam compared to phenytoin as effective in preventing post-traumatic seizures?	6.70 (5.9)	6.50 (1.8)
In children after cardiac arrest, do prophylactic anti-seizure drugs compared to no anti-seizure drugs, reduce the incidence of seizures and impact on other outcomes?	6.19 (5.7)	5.67 (1.7)
In children with meningoencephalitis, does intracranial pressure monitoring with targeted management of intracranial pressure and cerebral perfusion pressure, compared to standard medical management, impact on neurological outcome at 6 months and survival?	5.87 (5.2)	5.58 (1.8)
Cardiac surgical intensive care domain topics		
In term neonates with single ventricle or those post-op with low cardiac output syndrome (LCOS), does non-nutritive (trophic) feeding, compared to full enteral feeding, impact on Necrotising Enterocolitis (NEC) and other outcomes?	6.29 (2.1)	6.45 (1.6)

In children post cardiac surgery, do restrictive blood transfusion thresholds (<90g/L in cyanotic and <70g/L in non-cyanotic heart disease), compared to permissive blood transfusion thresholds (<110g/L cyanotic, <90g/L non-cyanotic), impact on organ dysfunction and costs?	6.15 (5.2)	6.11 (1.8)
In children after cardiac surgery with CPB, would a more liberal approach to enteral nutrition and/or oral fluids (ie exclude enteral feed/oral fluids from total restrictive allowance + diuretics), compared to standard severe total fluid restriction, impact on incidence of heart failure, fluid overload, length of ventilation and child distress?	6.10 (3.8)	6.05 (1.9)
In children after cardiac surgery, does monitoring with cerebral and somatic Near Infrared Spectroscopy (NIRS), compared to standard monitoring with no NIRS, impact on length of inotropic support, length of stay, length of ventilation and cardiac arrest or mortality?	5.94 (3.9)	5.84 (1.8)
In children post cardiac surgery (subgroups cyanotic v acyanotic), does enteral feeding compared to parenteral nutrition, impact on metabolomic profiles and nutritional outcomes?	5.71 (2.9)	5.69 (1.8)
In children after cardiac surgery with cardiopulmonary bypass (CPB), does fibrinogen concentrate supplementation in at risk patients, compared to no supplementation, impact on bleeding incidence and blood product usage?	5.64 (5.7)	5.5 (1.6)
Gut and Nutrition		
In mechanically ventilated children, does the use of gastro-protective drugs (e.g. ranitidine, omeprazole), compared to no use of gastro-protective drugs, impact on the incidence of ventilator-associated pneumonia, length of ventilation and length of stay?	6.19 (4.1)	6.29 (1.8)
In children on NIV, does post-pyloric (NJ) feeding, compared to standard gastric feeding, impact on energy target achievement, time to achieve full feeding or adverse events (VAP)?	6.14 (4.7)	6.09 (1.7)
In ventilated PICU children, does intermittent bolus feeding, compared to continuous feeds, impact on feed intolerance and time to achieve energy targets?	6.26 (3.6)	5.98 (1.8)
Renal, fluids and blood products		

In ventilated children, does the use of balanced crystalloids (Plasmalyte, Hartman's) compared to dextrose/saline maintenance solutions, impact on acute kidney injury and metabolic acidosis?	6.97 (2.9)	7.23 (1.7)
In ventilated children on PICU, would a more restrictive fluid intake (dry lung strategy) compared standard fluid allowance, impact on length of ventilation and mortality?	6.67 (6.1)	6.81(1.5)
In children on PICU with arterial lines, does saline flush solution, compared to heparinised saline flush solution, impact on line patency and duration of line?	6.10 (3.9)	5.96 (2.7)
In children on PICU requiring a transfusion, does a more restrictive threshold of <70g/l, compared to standard practice thresholds, impact on organ dysfunction, mortality and other outcomes?	6.07 (4.5)	5.82 (1.7)
In children on continuous renal replacement therapy (CRRT), do higher flow rates of 75-90mls/hr compared to standard flow rates of 30-45mls/hr, impact on length of ventilation, and change in hemodynamic and biochemical markers?	5.67 (4.8)	5.55 (1.7)
Sepsis and shock domain topics		
In PICU children on antibiotics for >48hours for suspected infection, does rapid pathogen identification and antibiotic rationalisation, compared standard practice, reduce the prevalence of antibiotic resistance and improve cost-effectiveness?	6.87 (6.2)	6.68 (1.9)
In PICU children with sepsis on inotropic support, does the administration of IV steroids, compared to no steroids, impact on length of ventilation and length of stay and other outcomes?	6.38 (6.0)	6.48 (1.8)
In children on PICU with shock requiring inotropes, does the use of adrenaline infusion, compared to dopamine infusion, impact on mortality, length of ventilation, need for renal replacement therapy and time to shock resolution?	5.90 (5.5)	6.44 (1.6)
In children on PICU with blood pressure <50th centile (hypotension), does targeting therapy to maintain blood pressure >5th centile, compared to standard management which targets therapy to maintain blood pressure >50th centile, impact on the length of ventilation, organ dysfunction and mortality?	6.43 (3.0)	6.43 (1.8)
In PICU children with sepsis /septic shock, would the early initiation of renal replacement therapy, compared to standard care, impact on length of ventilation, organ dysfunction and other outcomes?	6.45 (5.0)	6.27 (1.9)

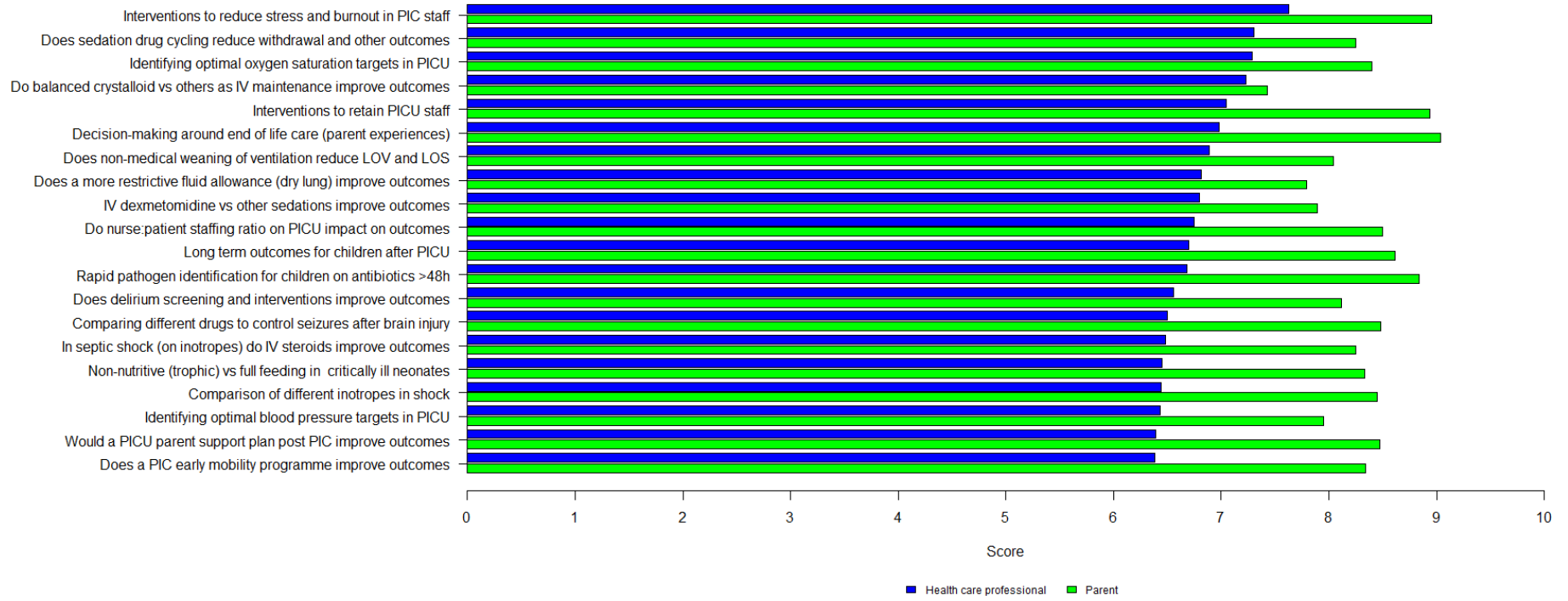
In children with catecholamine refractory septic shock, does early referral to ECLS centre, compared to continuing medical management, impact on survival, the length of ventilation, length of stay and organ dysfunction?	5.90 (5.3)	5.91 (1.8)
In children with 'warm' (vasoplegic) septic shock, does the use of angiotensin-2 as a vasoconstrictor, compared to the use of noradrenalin and vasopressin, impact on the need for CRRT, length of ventilation and length of stay?	5.76 (5.8)	5.70 (1.8)
Impact of PICU on the child, family and staff domain topics		
In PICU staff, would targeted interventions to reduce staff distress, compared to nothing, impact on Post-Traumatic Stress Disorder (PTSD), burnout, retention rates and moral distress?	7.22 (2.1)	7.63 (1.7)
In PICU staff, do targeted interventions to retain staff working in PICU, compare to nothing, impact on staff retention rates?	6.82 (3.2)	7.05 (1.7)
What are parents' experiences of conversations about life limitation?	6.79 (7.4)	6.98(1.9)
In children ventilated more than 48hr, would a standardised parent support plan, compared to standard care, improve psychological and functional outcomes in children and families after PICU discharge?	6.37 (6.4)	6.39 (1.8)
In PICU children, does an intervention to reduce psychological morbidity, compared to standard care, impact on PTSD, psychiatric morbidity in children and parents?	6.22 (2.8)	6.17 (1.7)
Do parents of long stay patients on PICU (>6 months) have different support needs to parents of children with shorter stays?	6.03 (5.2)	6.10 (2.0)
In parents of children on PICU, would weekly telephone support for 3 months post discharge, compared to standard (none), impact on PTSD, anxiety and depression in parents?	5.98 (3.8)	5.92 (1.9)
In PICU, does 'shared decision-making between parents and physicians, compared to standard care, improve the quality of decisions made and parental satisfaction with care?	5.79 (4.0)	5.63 (2.0)
What is the impact of PICU admission on siblings?	5.87 (7.3)	5.57 (2.0)

In parents of children on PICU, would having set rest breaks off the PICU, compared to standard open visiting (24-hour access), impact on parent wellbeing?	5.55 (3.1)	5.28 (1.9)
Safety, Quality, Service Improvement and outcomes domain topics		
In ventilated children on PICU with single organ failure, does 1:2 RN:patient ratio, compared to standard 1:1 ratio, impact on adverse events, costs and length of ventilation?	6.68 (2.9)	6.75 (1.7)
What are the short and longer-term physical, cognitive, functional and psychosocial outcomes of children after critical illness?	6.79 (2.9)	6.72 (1.8)
In critically ill children, does an early mobility intervention program, compared to no early mobility intervention, affect parental satisfaction perceived quality of life of their child, adverse events and staff satisfaction?	6.09 (2.2)	6.38 (1.6)
In all children having been on PICU, would routine follow up care post PICU discharge, compared to standard care of no follow up, be cost-effectiveness and impact on patient and parent outcomes?	6.21 (3.7)	6.24 (2.0)
In newly qualified nurses working on PICU, would a virtual reality simulation education program, compared to standard education, improve nurses' confidence levels, critical thinking skills and performance?	5.98 (2.8)	6.16 (1.7)
Development and validation of a quality of life assessment tool for children on long-term ventilation.	6.38 (7.4)	6.02 (2.1)
In children in hospital, does a critical care outreach team (CCOT), compared to no critical care outreach team, impact on PICU length of stay (in children admitted from within the hospital)?	5.84 (5.9)	5.75 (2.0)
In PICU, would nurse-led (evening) ward rounds, compared to standard medical-led ward rounds, impact on daily goal achievement, parent satisfaction, nurse knowledge level, and length of stay?	5.93 (3.7)	5.73 (1.8)

Both groups rated topics on a Likert scale 1 (lowest priority topic) – 10 (10 highest priority topic)

Abbreviations: CPB Cardiopulmonary Bypass; PICU Pediatric Intensive Care Unit; PTSD Post Traumatic Stress Disorder; CRRT Continuous Renal Replacement Therapy; ECLS Extracorporeal Life Support; IV Intravenous, NIV Non-invasive ventilation, NJ Naso-jejunal, VAP Ventilator Acquired Pneumonia; CPAP Continuous Positive Airway pressure; ARDS Acute Respiratory Distress Syndrome; Fio2 Fraction of Inspired Oxygen; SpO2 Arterial Oxygen saturation; ETT Endotracheal Tube; PEEP Positive End Expiratory pressure; DNase deoxyribonucleases; SD Standard Deviation.

Supplementary File 4



Supplementary File 5: New questions raised by parents mapped to the HCP generated research questions

Theme: A. Post-PICU outcomes		Link(s) to Top 20 research priority	Link to lower HCP priority research questions
1	Impact of ECLS and its use in very young/premature babies	Research into Paediatric Post Intensive Care Syndrome	
2	The effects of paralysis drugs on young infant, toddlers and babies.	<ul style="list-style-type: none"> • Research into Paediatric Post Intensive Care Syndrome • Identifying and treating delirium • Weaning from mechanical ventilation 	
3	Brain performance in infant, baby or toddlers after prolonged sedation	<ul style="list-style-type: none"> • Research into Paediatric Post Intensive Care Syndrome • Research to explore different ways to reduce sedation • Comparison of two sedation medicines 	
4	Impact of sedative medications on educational achievements	<ul style="list-style-type: none"> • Research into Paediatric Post Intensive Care Syndrome • Research to explore different ways to reduce sedation • Comparison of two sedation medicines 	
5	Visual and verbal stimulation and the impact on long term recovery.	Research into Paediatric Post Intensive Care Syndrome	
6	How does coordination of follow up care work best when children are treated in PICU out of their local area?	Research into Paediatric Post Intensive Care Syndrome and support for parents post PICU	Would weekly telephone support for 3 months post discharge vs. standard (none) impact on parent wellbeing?
7	Impact of a long term PICU stay on siblings and parents.	Research into Paediatric Post Intensive Care Syndrome	Does an intervention to reduce psychological morbidity vs. standard care

			<p>impact on PTSD, psychiatric morbidity in CYP & parents?</p> <p>What is the impact of PICU admissions on siblings?</p>
8	Noise levels/light levels on PICU.	<ul style="list-style-type: none"> • Research into Paediatric Post Intensive Care Syndrome • Reviewing and treating delirium 	
9	Research into the effects of morphine/ fentanyl/ketamine on children's mental health.	Research into Paediatric Post Intensive Care Syndrome	Does an intervention to reduce psychological morbidity vs. standard care impact on PTSD, psychiatric morbidity in CYP & parents?
10	Psychological support for patients post-PICU and the long-term effect on their mental health and recovery.	Research into Paediatric Post Intensive Care Syndrome	Does an intervention to reduce psychological morbidity vs. standard care impact on PTSD, psychiatric morbidity in CYP & parents?
Theme B: Care and Support of parents on / post PICU			
1	Research in after care for families after a long-term admission	Support for parents post PICU	<p>Do parents of long stay patients (>6months) have different support needs to parents of children with shorter stays</p> <p>Would weekly telephone support for 3 months post discharge vs standard (none) impact on parent wellbeing?</p>
2	Research on ways to reduce parental trauma/anxiety during PICU	Support for parents on PICU	Do parents of long stay patients (>6months) have different support needs to

			parents of children with shorter stays?
3	Research on the impact of multiple caregivers and communication with parents and caregivers during a PICU admission	Staffing models – impact on patients / families	Does shared decision-making between parents & physicians compared to standard care improve the quality of decision made and parental satisfaction with care?
4	Support for parents while on PICU	Support for parents on PICU	Do parents of long stay patients (>6months) have different support needs to parents of children with shorter stays?
5	Effects of being in NICU on maternal mental health and post-natal recovery	Support for parents on and post PICU	Does an intervention to reduce psychological morbidity vs standard care impact on PTSD, psychiatric morbidity in CYP & parents?
Theme C: Staffing and PICU care provision			
1	Research on the impact of consistent nursing staff/doctors looking after a child on PICU.	Staffing models – impact on patients / families	Does shared decision-making between parents & physicians compared to standard care improve the quality of decision made and parental satisfaction with care?
2	Research in the management of staff in PICU	<ul style="list-style-type: none"> •Research to address staff distress •Staff retention •Staff: patient ratios 	
3	Post-operative cardiac early goal directed therapy versus standard management	Targeted Blood pressure management	Would nurse led ward rounds vs medically led ward rounds impact on daily goal achievement, parent

			satisfaction, nurse knowledge levels and length of stay?
4	Early communication of expectations for chronically ill patients	Potential link to research exploring communication and decision-making about life limitation.	Does shared decision-making between parents & physicians compared to standard care improve the quality of decision made and parental satisfaction with care?
5	Non-invasive hats uncomfortable – design and test new ones that are better fit for patients.	Novel: equipment	

Abbreviations: CYP Children and Young Person; HCP Healthcare Professional; ECLS Extracorporeal Life Support; PIC Pediatric Intensive Care; NICU Neonatal Intensive Care Unit; PTSD Post Traumatic Stress Disorder;