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# National priority setting partnership using a Delphi consensus process to develop neonatal research questions suitable for practice-changing randomised trials in the UK

Katie Evans ,[1] Cheryl Battersby ,[1] James P Boardman ,[2] Elaine Boyle,[3,4] Will Carroll ,[5] Kate Dinwiddy,[6] Jon Dorling,[7] Katie Gallagher ,[8] Pollyanna Hardy,[9] Emma Johnston,[10] Helen Mactier ,[11] Claire Marcroft,[12] James William Harrison Webbe ,[1] Chris Gale [1]

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For numbered affiliations see end of article.

**Correspondence to**
Dr Chris Gale, Neonatal Medicine, School of Public Health, Faculty of Medicine, Imperial College London, London SW7 2AZ, UK; christopher.gale@imperial.ac.uk

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## ABSTRACT

**Background** The provision of neonatal care is variable and commonly lacks adequate evidence base; strategic development of methodologically robust clinical trials is needed to improve outcomes and maximise research resources. Historically, neonatal research topics have been selected by researchers; prioritisation processes involving wider stakeholder groups have generally identified research themes rather than specific questions amenable to interventional trials.

**Objective** To involve stakeholders including parents, healthcare professionals and researchers to identify and prioritise research questions suitable for answering in neonatal interventional trials in the UK.

**Design** Research questions were submitted by stakeholders in population, intervention, comparison, outcome format through an online platform. Questions were reviewed by a representative steering group; duplicates and previously answered questions were removed. Eligible questions were entered into a three-round online Delphi survey for prioritisation by all stakeholder groups.

**Participants** One hundred and eight respondents submitted research questions for consideration; 144 participants completed round one of the Delphi survey, 106 completed all three rounds.

**Results** Two hundred and sixty-five research questions were submitted and after steering group review, 186 entered into the Delphi survey. The top five ranked research questions related to breast milk fortification, intact cord resuscitation, timing of surgical intervention in necrotising enterocolitis, therapeutic hypothermia for mild hypoxic ischaemic encephalopathy and non-invasive respiratory support.

**Conclusions** We have identified and prioritised research questions suitable for practice-changing interventional trials in neonatal medicine in the UK at the present time. Trials targeting these uncertainties have potential to reduce research waste and improve neonatal care.

### WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There is wide variability in neonatal care across the UK.
⇒ Robust, high-quality interventional trials are the optimal approach to improving the evidence base and reducing variability in neonatal care.
⇒ It is important to involve parents and other stakeholders in identifying important future research topics but this can be challenging and alternate approaches need to be developed.

### WHAT THIS STUDY ADDS

⇒ Previous prioritisation processes have identified broad themes of interest; this study identifies specific research questions suitable for answering in interventional trials.

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This prioritised list of specific research questions can be used by research organisations to support and develop practice-changing interventional trials within neonatology.

## INTRODUCTION

Neonatal clinical care varies widely,[1] in part due to an incomplete evidence base for many treatments and approaches.[2] The optimal way to resolve uncertainties in healthcare is through well-designed randomised controlled trials (RCTs).[3] Such interventional studies require structured research questions that describe the participants, intervention(s), comparator and outcomes of the trial. These components of the research question are commonly referred to as the 'PICO question'.[4] Multiple neonatal research questions are potentially amenable to RCTs; however, trials must be selected carefully because they are expensive and often require large numbers of the target population to participate, which can have co-enrolment consequences for other research. There is a clear need to identify and prioritise research questions; this can be achieved through priority setting involving key stakeholders.

Priority setting partnerships have been used throughout perinatal medicine and demonstrate the value of involving key stakeholders such as parents, patients and healthcare professionals alongside researchers.[5] Such partnerships, notably led by the James Lind Alliance,[6] have addressed topics

including preterm birth,[7 8] stillbirth,[9] childhood neurological conditions,[10] diabetes in pregnancy[11] and pregnancy hypertension[12] to help guide future research directions. These priority setting partnerships have been invaluable for identifying broad research themes but are rarely detailed enough to yield specific research questions suitable for interventional trials.

To reduce research waste, clinical uncertainties should be evaluated wherever possible through definitive randomised trials with sufficient power and methodological robustness to provide answers that inform clinical practice.[13] This initiative aimed to identify and prioritise neonatal research questions suitable for evaluation in definitive interventional trials using the more detailed and granular PICO format. Through a transparent, reproducible and inclusive methodology, this process aimed to support development and commissioning of practice-changing interventional trials in neonatology, to address those questions most important to healthcare professionals, parents and researchers.

## METHODS

A steering group guided the development and conduct of this work, including representatives from academia, key neonatal organisations, clinical neonatology, neonatal nursing, allied healthcare professionals (AHPs), statisticians and parents with experience of neonatal care (online supplemental text 1). The protocol was designed collaboratively and published prior to data analysis.[14]

### Scope

The scope of the prioritisation process was developed and agreed by the steering group. Research questions had to be relevant to high-income neonatal care settings and proposed interventions expected to be delivered by neonatal teams. This included care provided on delivery suites, neonatal units, transitional care units and postnatal wards, during neonatal transport and within the community by neonatal teams after inpatient neonatal care. Research at pre-RCT stages of the translational pipeline was outside the scope of the process.

### Overview

Established research priority setting methodology as outlined by the James Lind Alliance was modified by the steering group to focus on detailed PICO questions, rather than general research themes or outcomes.

Phase 1: identification of neonatal research questions suitable for addressing in RCTs.

Phase 2: review of submitted neonatal research questions to remove duplicate questions and previously answered questions.

Phase 3: prioritisation of neonatal research questions by all relevant stakeholders using a three-round eDelphi process.

Phase 4: dissemination of ranked list of research questions in PICO format.

### Participants

The following participant groups were recruited for involvement in both the question submission and the Delphi prioritisation:

1. Clinicians involved in neonatal care: neonatologists, paediatricians, trainee doctors, neonatal nurses and advanced neonatal nurse practitioners were contacted through professional organisations including the British Association of Perinatal Medicine (BAPM), the Neonatal Nurses Association and the Neonatal Society, through organisational websites, direct email correspondence with members, regional teaching and meetings and social media.
2. AHPs involved in neonatal care: occupational therapists, physiotherapists, dietitians, speech and language therapists and clinical psychologists were contacted through the Association of Paediatric Chartered Physiotherapists, Royal College of Occupational Therapists, British Dietetic Association and Royal College of Speech and Language Therapists through websites, regional and national meetings and social media.
3. Researchers: academics and researchers working within neonatology were contacted through the Neonatal Society, other existing research networks, regional and national meetings and through clinical trial units with a neonatal interest.
4. Parents and former neonatal patients: parents, former patients and family members with experience of neonatal care were contacted through the national care coordinator groups, Maternity Voices Partnerships, relevant charity and advocacy websites and through social media.

We requested and recorded basic background descriptive data from participants. By ongoing monitoring of these data throughout the study, we aimed to ensure representation across the different stakeholder groups and of diverse social and ethnic groups—targeting under-represented groups accordingly. Recruitment was international, with participants requested to have personal experience of neonatal care or research in high-income settings.

### Question design and submission

A bespoke platform for question submission was devised using 'OnlineSurvey' (Jisc Services Limited, UK) software, with iterative development and face validity testing from all steering group members. The platform guided participants through the practicalities of structuring questions in the PICO format. We used categorical variables for gestational age and geographical location in the population (P) domain alongside a free-text field and used free-text fields for intervention (I) and comparison (C) domains. Outcomes could be selected from a categorical variable populated with the Core Outcomes in Neonatology[15] or through a free-text field (online supplemental figure 1). We recognised generating research questions using the PICO structure could be challenging for some participants; therefore, the following strategies were developed:

1. An example PICO question based on a well-known neonatal trial was displayed on the question submission platform.
2. Pre-recorded video resources were developed for the BAPM website, showing members of the steering group putting together a PICO question relevant to their branch of practice. Links to these resources were included on the question submission software.
3. Two BAPM-supported webinars were held, explaining the development of PICO questions: one targeted towards all participants and one specifically designed to support parents and former patients led by a parent representative.

We contacted other groups who had undertaken neonatal priority setting work (for example, related to neonatal transport) directly and included relevant research questions in PICO format.

Each submitted question was reviewed by two independent members of the steering committee to remove questions that were incomplete, duplicate, out of scope, unclear or already answered, prior to progression to the eDelphi.

## Prioritisation process

All eligible research questions were entered into a three-round eDelphi survey using 'DelphiManager' (Comet Initiative Delphi Manager, University of Liverpool, UK) software, to establish a consensus as to their importance. Participants were asked to rank each research question on a 9-point Likert scale with 1 representing 'no importance' and 9 representing 'critical importance'. After completion of round one, participants could suggest additional questions in PICO format which underwent the same review process as existing questions and were added to the second round of the eDelphi. Due to the large number of research questions, the second and third rounds of the eDelphi were limited to the top 75 and 50 ranked questions, respectively, to help minimise attrition rates. In the third round, the ranking by individual stakeholder group was displayed using the DelphiManager software (online supplemental figure 2) so that participants could choose to alter their answers based on the views of others. Analysis involved results being ranked by mean scores across all the stakeholder groups combined.

## Parental and former patient involvement

To maximise accessibility for non-clinical participants, guidance was provided by the study steering group parent representative throughout the prioritisation process. Advice was sought from key advocacy organisations such as Bliss to determine how best to meaningfully involve parents and ex-neonatal patients while keeping questions specific enough to be addressed in interventional trials. In addition to the well-attended focused parental webinar already described, videos of sample PICO questions were recorded by different stakeholders including a parent with experience of neonatal care. Publicity for involvement in the Delphi stages of the questionnaire was supported by a range of organisations including Maternity Voices Partnerships, local parent groups and relevant advocacy and charitable groups.

# RESULTS

The national neonatal priority setting partnership was completed as outlined in the study protocol.[14]

**Table 1** Participant characteristics

| | Question submission | eDelphi survey | |
|---|---|---|---|
| Total number of participants | 265 | 144 | |
| Stakeholder group | | | |
| Parents/former patients | 30 (11%) | 13 (9%) | |
| Nurses/allied healthcare professionals | 38 (14%) | 42 (29%) | |
| Doctors/researchers | 169 (64%) | 89 (62%) | |
| Other | 28 (11%) | 0 (0%)* | |
| Gender | | | |
| Male | 73 (28%) | 41 (29%) | |
| Female | 163 (62%) | 103 (71%) | |
| Prefer not to say | 29 (10%) | 0 (0%)* | |
| Ethnicity | | | Census[2021] |
| Asian/Asian British | 24 (9%) | 20 (14%) | 9.30% |
| Black/African/Caribbean/black British | 8 (3%) | 4 (3%) | 4.00% |
| Mixed/multiple ethnic | 10 (4%) | 5 (3%) | 2.90% |
| White | 181 (68%) | 108 (75%) | 81.70% |
| Other | 42 (16%) | 7 (5%) | 2.10% |

*'Other' not included as an option in the eDelphi survey.

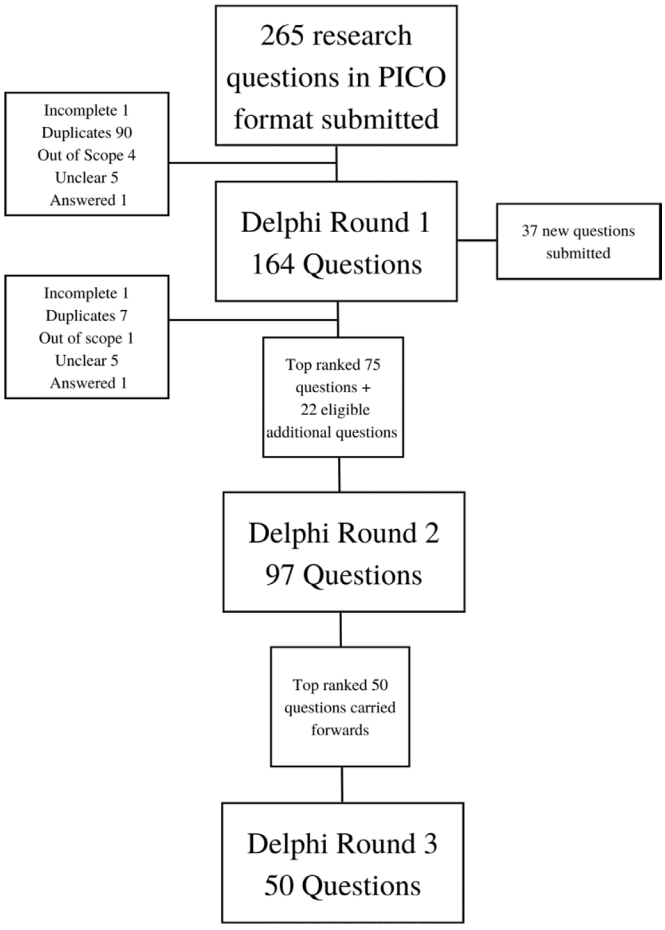


**Figure 1** Flow chart of question identification and eDelphi consensus process. PICO, population, intervention, comparison, outcome.

## Question development

Two hundred and sixty-five questions were submitted in PICO format during the 1-month submission period, from a total of 108 participants. The most common themes for questions were feeding and nutrition (20%) and family integrated care (20%). Stakeholder group breakdown was 11% parents, 4% nurses, 49% doctors, 11% AHPs, 15% researchers and 11% other (table 1). The flow of research questions throughout the study is represented in figure 1.

## eDelphi survey

The three-phase online Delphi survey opened in May and was completed in August 2022; over 200 participants registered their interest. One hundred and sixty-four questions were eligible for entry into the first round of the survey which was completed by 144 participants. Raw scores displayed a bimodal distribution when compared across stakeholder groups with a clear consensus regarding those deemed more important (figure 2). Attrition rates across the three rounds were highest between rounds one and two (21.5%) and lower between rounds two and three (6.2%). Within individual stakeholder groups, attrition rates were highest in parents and former patients (53.9%), followed by nursing and AHPs (47.5%) and doctors and researchers (13.7%).

Thirty-seven new questions were submitted during round one of the eDelphi; 22 of these were deemed eligible for entry into round two. The results of round three displayed similar concordance between stakeholder groups, although with a higher

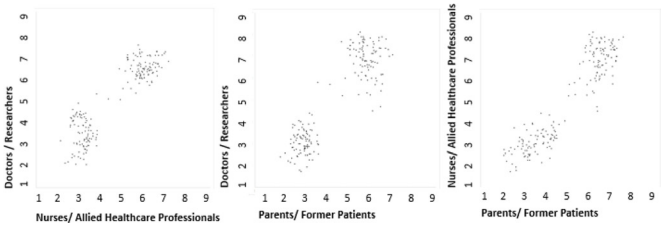


**Figure 2** Prioritisation of research questions by stakeholder groups across round two of the eDelphi.

consensus between the clinical groups (figure 3) than between clinical and parent/patient groups.

### Final list of prioritised research questions

All eligible questions were amalgamated into a final list of prioritised research questions and can be viewed in online supplemental text 2. The top 10 most highly ranked questions are displayed in table 2.

## DISCUSSION

Using a robust, reproducible consensus methodology, we have identified and prioritised 186 neonatal research questions suitable for definitive interventional clinical trials. Through involvement of a broad range of stakeholders, the results are generalisable to the wider neonatal community in the UK. These results should inform the design of practice-changing clinical trials to ensure such trials address clinically relevant research questions and avoid contributing to research waste.[16]

This neonatal research priority setting partnership builds on previous priority setting work by Duley *et al*,[7] which identified 15 broad themes of interest for research related to preterm birth, such as reducing infections, necrotising enterocolitis (NEC) and bronchopulmonary dysplasia. The detailed research questions prioritised in this work align closely with these broad research themes, particularly the importance of preventing NEC. Our work widens the scope by including research questions relating to all infants requiring neonatal care and is distinct in providing more granular and detailed research questions suitable for answering in practice-changing interventional trials.

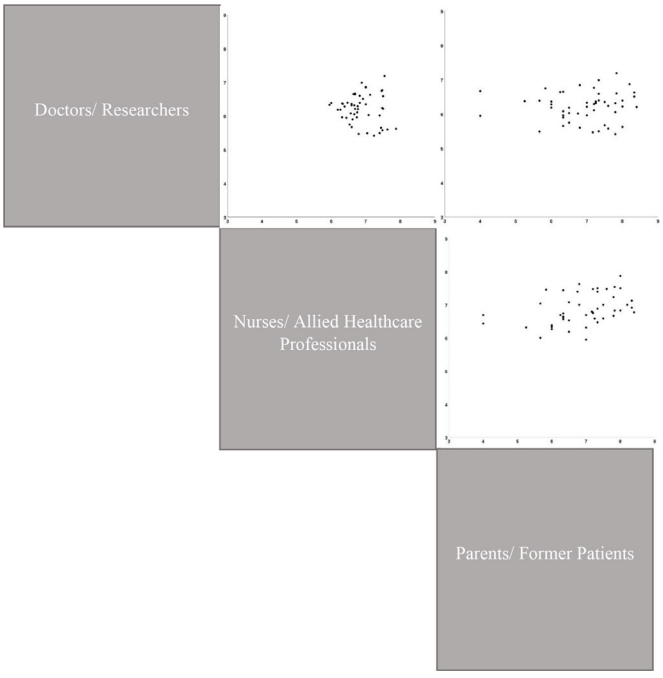


**Figure 3** Stakeholder variability on round three of the eDelphi. Pairwise comparisons by stakeholder group of the ranked mean scores from round three for each outcome. Multiple pairwise comparisons presented together to aid visualisation. Comparisons arranged so that they are vertically or horizontally aligned to the stakeholder group label.

A strength of this project is the large numbers of participants: over 200 people from several different high-income countries identified and ranked research questions. Additional strengths include ongoing parent representation with the use of specially designed training materials and question submission software supporting involvement in designing PICO questions. Finally, the use of a well-established, transparent eDelphi methodology ensures that this process was robust and reproducible for use in future initiatives. This approach could be used to identify and prioritise research questions suitable for other methodologies such as qualitative research.

A limitation of this work was attrition during the eDelphi survey, which was most notable among parents and former patients. Ensuring ongoing parent, patient or public participation in Delphi surveys is well recognised to be challenging.[17] Attrition rates are lower if patient recruitment is through treatment centres rather than patient charities and advocacy organisations[18]; however, in previous neonatal priority setting work,[7] neonatal unit-based recruitment of parents was also challenging,[8] hence was not pursued during this study. We recognise that the lower levels of participation from parents and former patients may have influenced our final results, but a clear bimodal distribution of rankings with significant clustering of the same top-ranked and lower-ranked questions was consistent across all stakeholder groups. Given the small differences seen in mean rankings among highly prioritised research questions, these should be considered together as a group, with less emphasis on exact position in the ranking (online supplemental table 2) when planning future research.

We recognised at the outset that meaningful involvement in prioritisation required complex medical and technical knowledge of neonatal medicine, and that this knowledge may not be easily accessible to parents and ex-neonatal patients. We did however endeavour to include parents and ex-neonatal patients as they are key stakeholders in research designed to resolve uncertainties about the use of existing treatments. A different process would be needed to prioritise RCTs of emerging new therapies at earlier stages of translation. Following engagement with our parental representative and the organisation charity Bliss, we attempted specific and targeted parental prioritisation using plain English summaries of the most highly ranked questions. However, even this approach was considered inappropriate by our parent representative and charity partners who concluded that for parental involvement to be truly meaningful, it should be addressed by a more targeted qualitative approach focused on smaller numbers of research questions. Therefore, while robust health professional input was obtained from the full range of neonatal clinical and allied professions, this process should be considered less representative of parent and ex-neonatal patient views.

Priority setting work is becoming more widespread, with a recent scoping review showing that health-related topics encompassed 93% of all priority setting projects completed by the end of 2020.[19] To our knowledge, the work to date has focused on identification of research themes or areas of interest, rather than targeting questions structured in a PICO format. Some studies have reformatted themes into PICO questions[20]; however, these have then been prioritised through a consensus group workshop,

**Table 2** Final list of top 10 prioritised research questions

| Ranking | Question | Final mean score |
|---|---|---|
| 1 | Does routine fortification of human milk feeds improve necrotising enterocolitis and long-term neurodevelopmental outcomes in preterm babies? | 7.305 |
| 2 | In preterm and term babies requiring resuscitation, does intact cord resuscitation improve survival and brain injury compared with standard resuscitation with early cord clamping? | 6.990 |
| 3 | In babies diagnosed with necrotising enterocolitis, does earlier surgical intervention improve survival, brain injury and quality of life compared with standard practice? | 6.959 |
| 4 | Does therapeutic hypothermia (cooling) reduce brain injury and improve general cognition in babies with mild hypoxic ischaemic encephalopathy compared with standard care? | 6.920 |
| 5 | In extremely preterm infants (<28 weeks' gestation at birth), should we routinely use non-invasive positive pressure ventilation or continuous positive airway pressure as the primary mode of respiratory support to improve survival and reduce bronchopulmonary dysplasia? | 6.867 |
| 6 | Is early breastmilk fortification or late breastmilk fortification superior with regard to outcomes such as necrotising enterocolitis in preterm babies? | 6.857 |
| 7 | In preterm babies, do probiotics improve survival, sepsis and necrotising enterocolitis? | 6.838 |
| 8 | Does human-derived milk fortifier rather than bovine-derived milk fortifier improve outcomes such as necrotising enterocolitis in preterm babies? | 6.838 |
| 9 | In very preterm infants at delivery, does physiological-based cord clamping (ie, stabilisation or resuscitation with the cord intact and only clamping when heart rate is >100 beats/min and oxygen saturation >85% in an inspired oxygen concentration of <0.4) versus time-based clamping at 60 s (or earlier if stabilisation or resuscitation is needed) increase survival without disability? | 6.714 |
| 10 | In preterm infants with insufficient maternal milk available, does the use of pasteurised human milk (donor) as compared with preterm formula reduce necrotising enterocolitis requiring surgery and improve 2-year neurodevelopmental outcomes? | 6.705 |

rather than with widespread stakeholder involvement. We believe our study is among the first to solely invite submission and prioritisation of research questions in PICO format suitable for answering in definitive interventional trials. Although outside the scope of this study, we recognise that well-designed RCTs should include qualitative elements to ensure that parental and patient experiences are captured, improving consent processes and overall success.

Future steps include sharing these prioritised research questions with clinical trial funders through existing commissioning processes. Our study methods and training materials strove to support detailed PICO question formation; however, we recognise some questions will require further refinement prior to evaluation in perinatal and neonatal adaptive trial platforms. Utilisation of priority setting results by research funders is expanding rapidly and there is variation in the methods used.[21] Within high-income neonatal settings such as the National Health Service, this list will provide inspiration for the planning, design, funding and performance of future practice-changing trials.

## CONCLUSION

We have identified a prioritised list of detailed neonatal research questions suitable for addressing in interventional trials. Involvement of a broad range of stakeholder groups has ensured relevance to the wider neonatal community. The results of this prioritisation process will help guide future funding and development of interventional trials to ensure that they address questions of clinical import, change clinical practice and reduce research waste.

**Author affiliations**
[1]School of Public Health, Faculty of Medicine, Neonatal Medicine, Imperial College London, London, UK
[2]Neonatal Medicine, The University of Edinburgh MRC Centre for Reproductive Health, Edinburgh, UK
[3]Neonatal Medicine, University of Leicester, Leicester, UK
[4]Neonatal Clinical Studies Group, National Institute for Health and Care Research, London, UK
[5]Child Health, Keele University, Keele, UK
[6]British Association of Perinatal Medicine, London, UK
[7]Department of Neonatal Medicine, University Hospital Southampton NHS Foundation Trust, Southampton, UK
[8]EGA Institute for Women's Health, University College London, London, UK
[9]Policy Research Unit in Maternal Health & Care, National Perinatal Epidemiology Unit Clinical Trials Unit, University of Oxford, Oxford, UK
[10]Parents and Family Engagement Lead, Thames Valley and Wessex Operational Delivery Network, Thames Valley and Wessex, UK
[11]Neonatal Medicine, University of Glasgow, Glasgow, UK
[12]Neonatal Physiotherapy, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK

**Correction notice** This paper has been amended since it was first published. An additional funding statement has been added in the competing interests section.

**Twitter** Katie Evans @KatieE1066, Cheryl Battersby @DrCBattersby, Helen Mactier @HMactier and Chris Gale @DrCGale

**Contributors** CG and CB conceived this project. KE, JPB, HM, CG and CB planned and coordinated the initial steering group and protocol. KD provided administrative support. The first draft of the manuscript was written by KE and revised by JPB, EB, WC, JD, KG, PH, EJ, HM, JWHW and CG (guarantor). It was approved by all members of the steering group.

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**Competing interests** CG is vice chair of the NIHR Research for Patient Benefit London Regional Advisory Panel and a member of the Glasgow Children's Hospital Charity External Panel; he holds a Medical Research Council Transition Support Award. JPB is a member of the Wellcome Trust's Career Development Award Panel and the Great Ormond Street Hospital Charity Research Assessment Panel. CB is the NIHR deputy chair of HTA prioritisation committee for hospitals. JD is a member of the NIHR HTA CET Funding Committee. CM is funded by HEE-NIHR Integrated Clinical Academic Programme and holds an NIHR ICA CSRF Fellowship. KE was supported by a Chelsea and Westminster NHS Foundation Trust Neonatal Clinical Research Fellow Programme.

**Patient consent for publication** Not required.

**Ethics approval** Research Ethics Committee approval was not required as the study did not recruit participants.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as supplemental information. All data relevant to this study are uploaded as supplemental information.

**ORCID iDs**
Katie Evans http://orcid.org/0000-0002-0503-9807
Cheryl Battersby http://orcid.org/0000-0002-2898-553X
James P Boardman http://orcid.org/0000-0003-3904-8960
Will Carroll http://orcid.org/0000-0003-2742-1836
Katie Gallagher http://orcid.org/0000-0002-6847-9594
Helen Mactier http://orcid.org/0000-0001-6154-5758
James William Harrison Webbe http://orcid.org/0000-0001-8546-3212
Chris Gale http://orcid.org/0000-0003-0707-876X

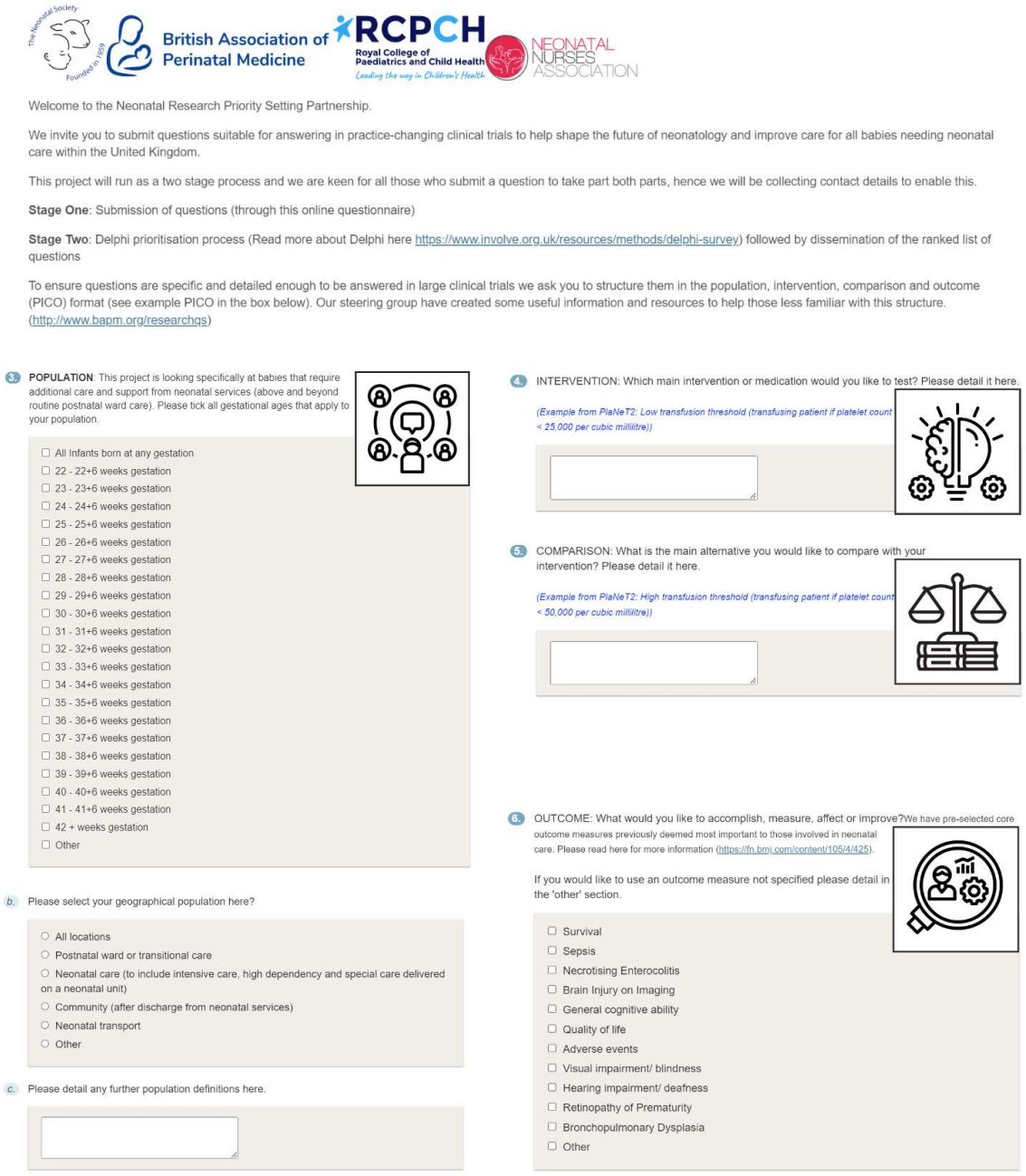
## REFERENCES

1 Pierrat V, Burguet A, Marchand-Martin L, *et al*. Variations in patterns of care across neonatal units and their associations with outcomes in very preterm infants: the french EPIPAGE-2 cohort study. *BMJ Open* 2020;10:e035075.
2 Willhelm C, Girisch W, Gottschling S, *et al*. Systematic Cochrane reviews in neonatology: a critical appraisal. *Pediatrics & Neonatology* 2013;54:261–6.
3 Akobeng AK. Understanding randomised controlled trials. *Arch Dis Child* 2005;90:840–4.
4 Miller SA, Forrest JL. Enhancing your practice through evidence-based decision making: PICO, learning how to ask good questions. *Journal of Evidence Based Dental Practice* 2001;1:136–41.
5 Partridge N, Scadding J. The James Lind alliance: patients and clinicians should jointly identify their priorities for clinical trials. *Lancet* 2004;364:1923–4.
6 About priority setting partnerships. n.d. Available: https://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm
7 Duley L, Uhm S, Oliver S, *et al*. Top 15 uk research priorities for preterm birth. *Lancet* 2014;383:2041–2.
8 Oliver S, Uhm S, Duley L, *et al*. Top research priorities for preterm birth: results of a prioritisation partnership between people affected by preterm birth and healthcare professionals. *BMC Pregnancy Childbirth* 2019;19:528.
9 Heazell AEP, Whitworth MK, Whitcombe J, *et al*. Research priorities for stillbirth: process overview and results from UK stillbirth priority setting partnership. *Ultrasound Obstet Gynecol* 2015;46:641–7.
10 Childhood neurological conditions priority setting partnership. n.d. Available: https://bpna.org.uk/?page=childhood-neurology-priority-setting-project
11 Ayman G, Strachan JA, McLennan N, *et al*. The top 10 research priorities in diabetes and pregnancy according to women, support networks and healthcare professionals. *Diabet Med* 2021;38:e14588.
12 Ho A, Webster L, Bowen L, *et al*. Research priorities for pregnancy hypertension: a UK priority setting partnership with the James Lind alliance. *BMJ Open* 2020;10:e036347.
13 Macleod MR, Michie S, Roberts I, *et al*. Biomedical research: increasing value, reducing waste. *The Lancet* 2014;383:101–4.
14 Evans K, Battersby C, Boardman JP, *et al*. National priority setting partnership using a delphi consensus process to develop neonatal research questions suitable for practice-changing randomised trials in the United Kingdom. *BMJ Open* 2022;12:e061330.
15 Webbe JWH, Duffy JMN, Afonso E, *et al*. Core outcomes in neonatology: development of a core outcome set for neonatal research. *Arch Dis Child Fetal Neonatal Ed* 2020;105:425–31.
16 Chalmers I, Bracken MB, Djulbegovic B, *et al*. How to increase value and reduce waste when research priorities are set. *The Lancet* 2014;383:156–65.
17 Dworkin J, Hessel H, Gliske K, *et al*. A comparison of three online recruitment strategies for engaging parents. *Fam Relat* 2016;65:550–61.
18 Barrington H, Young B, Williamson PR. Patient participation in Delphi surveys to develop core outcome sets: systematic review. *BMJ Open* 2021;11:e051066.
19 Grill C. Involving stakeholders in research priority setting: a scoping review. *Res Involv Engagem* 2021;7:75.
20 Smith EMD, Egbivwie N, Cowan K, *et al*. Research priority setting for paediatric rheumatology in the UK. *The Lancet Rheumatology* 2022;4:e517–24.
21 Noorani HZ, Husereau DR, Boudreau R, *et al*. Priority setting for health technology assessments: a systematic review of current practical approaches. *Int J Technol Assess Health Care* 2007;23:310–5.

**Online supplementary eText 1:** Members of the Neonatal Priority Setting Partnership Steering Group.

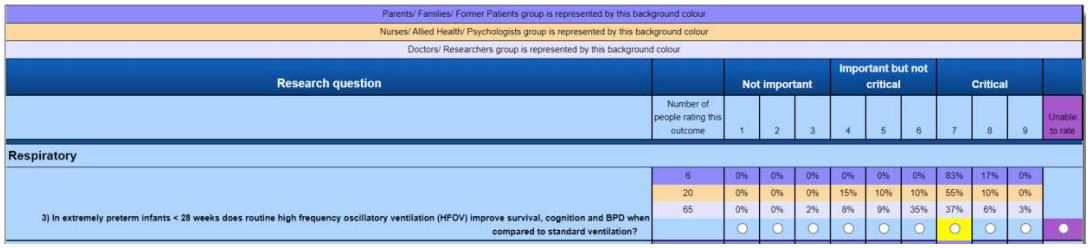
| **Steering Group Member** | **Role and affiliation** |
|---|---|
| Cheryl Battersby (CB) | Academic Neonatologist, British Association of Perinatal Medicine (BAPM) Data/Informatics lead & member of NIHR prioritisation committee. |
| James Boardman (JPB) | Professor of Neonatal Medicine and immediate past president of the Neonatal Society. |
| Elaine Boyle (EB) | Professor of Neonatal Medicine and Chair of the National Institute for Health Research Neonatal Clinical Studies Group. |
| William Carroll (WC) | Consultant Paediatrician and Royal College of Paediatrics and Child Health (RCPCH) officer for Research. |
| Jon Dorling (JD) | Professor of Paediatrics, Neonatal Consultant and BAPM research lead. |
| Kate Dinwiddy (KD) | Chief Executive of BAPM. |
| Katie Evans (KE) | Project Co-ordinator and Honorary Clinical Research Fellow in Neonatal Medicine. |
| Chris Gale (CG) | Professor of Neonatal Medicine and Neonatal Society Meeting Secretary. |
| Katie Gallagher (KG) | Academic Neonatal Nurse and Neonatal Nurses Association representative. |
| Pollyanna Hardy (PH) | Clinical Trials Statistician and Director of National Perinatal Epidemiology Unit Clinical Trials Unit. |
| Emma Johnston (EJ) | Parent representative and Parents and Family engagement Lead with the Thames Valley and Wessex Operational Delivery Network. |
| Helen Mactier (HM) | Consultant Neonatologist, Honorary Clinical Associate Professor and immediate past president of BAPM. |
| Claire Marcroft (CM) | Neonatal Physiotherapist and Allied Health Professionals Representative. |
| James Webbe (JW) | Trainee representative and Neonatal Medicine Trainee. |

**Online Supplementary eFigure 1:** Question submission software designed to support participants with submission of research questions in a population, intervention, comparison, outcome (PICO) structure.



**Online Supplementary eFigure 2:** Example of Round 3 eDelphi view.

Different Stakeholder Groups average rankings were colour coded (Purple for parents/ former patients, Orange for nurses/ allied healthcare and grey for doctors/ researchers) . This was explained to participants in the key above each speciality domain and also in the introductory paragraph of the priority setting exercise.



Parents/ Families/ Former Patients group is represented by this background colour

Nurses/ Allied Health/ Psychologists group is represented by this background colour

Doctors/ Researchers group is represented by this background colour

| Research question | | Not important | | | Important but not critical | | | Critical | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Number of people rating this outcome | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Unable to rate |
| **Respiratory** | | | | | | | | | | | |
| | 6 | 0% | 0% | 0% | 0% | 0% | 0% | 83% | 17% | 0% | |
| | 20 | 0% | 0% | 0% | 15% | 10% | 10% | 55% | 10% | 0% | |
| | 65 | 0% | 0% | 2% | 8% | 9% | 35% | 37% | 6% | 3% | |
| 3) In extremely preterm infants < 28 weeks does routine high frequency oscillatory ventilation (HFOV) improve survival, cognition and BPD when compared to standard ventilation? | | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ● |

Bronchopulmonary Dysplasia (BPD)

**Online Supplementary eText 2:** Full list of prioritised research questions.

Final mean scores displayed by individual stakeholder groups alongside final mean scores.

## Highly Prioritised Questions

| Rank | Question | Doctors/ Researchers | Nurses/ AHPs | Parents/ Former Patients | Mean Score |
|---|---|---|---|---|---|
| | **Round 3** | | | | |
| 1 | Does routine fortification of human milk feeds improve necrotising enterocolitis and long-term neurodevelopmental outcomes in preterm babies? | 7.187 | 7.542 | 7.833 | **7.305** |
| 2 | In preterm and term babies requiring resuscitation; does intact cord resuscitation improve survival and brain injury compared to standard resuscitation with early cord clamping? | 6.987 | 6.882 | 7.333 | **6.990** |
| 3 | In babies diagnosed with necrotising enterocolitis does earlier surgical intervention improve survival; brain injury and quality of life compared to standard practice? | 6.867 | 7.000 | 8.200 | **6.959** |
| 4 | Does therapeutic hypothermia (cooling) improve brain injury and general cognition in babies with mild hypoxic ischaemic encephalopathy (HIE) compared to standard care? | 6.763 | 7.474 | 7.200 | **6.920** |
| 5 | In extremely preterm infants < 28 weeks should we routinely use non-invasive positive pressure ventilation (NIPPV) or continuous positive airway pressure (CPAP) as the primary mode of respiratory support to improve survival and reduce bronchopulmonary dysplasia (BPD)? | 6.842 | 7.000 | 6.800 | **6.867** |
| 6 | Is early breastmilk fortification or late breastmilk fortification superior with regards to outcomes such as necrotising enterocolitis in preterm babies? | 6.767 | 7.458 | 5.822 | **6.857** |
| 7 | In preterm babies do probiotics improve survival; sepsis and necrotising enterocolitis? | 6.627 | 7.125 | 8.333 | **6.838** |
| 8 | Does human-derived milk fortifier rather than bovine-derived milk fortifier improve outcomes such as necrotising enterocolitis in preterm babies? | 6.587 | 7.500 | 7.333 | **6.838** |
| 9 | In very preterm infants at delivery does physiological based cord clamping (i.e. stabilisation or resuscitation with the cord intact and only clamping when heart | 6.600 | 6.824 | 7.833 | **6.714** |

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| | rate is> 100 beats per minute and oxygen saturation >85% in FiO2 <0.4) versus time-based clamping at 60 seconds (or earlier if stabilisation or resuscitation is needed) increase survival without disability? | | | | |
| 10 | In preterm infants with insufficient maternal milk available; does the use of pasturised human milk (donor) as compared with preterm formula reduce necrotising enterocolitis requiring surgery and improve two-year neurodevelopmental outcomes? | 6.507 | 6.917 | 8.333 | **6.705** |
| 11 | In any baby with seizures does levetiracetam improve need for second-line anti-convulsants when compared to phenobarbitone? | 6.649 | 6.643 | 6.333 | **6.637** |
| 12 | In term infants with a bilious vomit who are assessed by a senior neonatologist as being well; does transfer to a specialised unit for urgent upper gastrointestinal contrast improve survival; quality of life and adverse events compared to close clinical monitoring by the local neonatal team? | 6.640 | 6.688 | 6.250 | **6.632** |
| 13 | In babies above 34 weeks gestation on the postnatal ward; is a blood glucose threshold of 2.0mmol/L non-inferior to a blood glucose threshold of 2.6mmol/L with regards to adverse events? | 6.667 | 6.688 | 4.000 | **6.585** |
| 14 | In infants born extremely preterm (< 28 weeks) does 1 to 1 nursing care until 28 weeks corrected gestation improve survival and all core neonatal outcomes compared to standard nursing allocations based on intensive care support required? | 6.392 | 6.826 | 8.000 | **6.582** |
| 15 | In babies born preterm does a post-discharge home intervention package of brain stimulation exercises improve neurodevelopment when compared to standard care? | 6.216 | 7.500 | 8.000 | **6.551** |
| 16 | Does therapeutic hypothermia (cooling) improve brain injury and long term neurodevelopmental outcomes in preterm infants (> 30 weeks) who have suffered a hypoxic injury? | 6.237 | 7.474 | 7.600 | **6.540** |
| 17 | In infants with a prenatally diagnosed gastrointestinal anomaly does planned delivery in a unit with co-located neonatal surgical unit (no ambulance transfer required) improve survival; parental experience and adverse events? | 6.347 | 7.000 | 7.500 | **6.505** |
| 18 | In preterm babies does high dose caffeine (10-20mg/kg/day) improve survival; brain injury and cognition compared to low dose caffeine (5mg/kg/day)? | 6.316 | 6.667 | 7.800 | **6.455** |

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| 19 | In preterm infants does enhanced monitoring from birth to 72 hours of life (with near infrared spectroscopy (NIRS); transcutaneous CO2; spO2; heart rate and arterial BP) improve core neonatal outcomes compared to standard monitoring? | 6.395 | 6.471 | 7.333 | **6.434** |
| 20 | In extremely preterm infants that are ventilator dependent does early dexamethasone treatment (2 weeks of age) compared to late dexamethasone treatment (4 weeks of age) improve survival; bronchopulmonary dysplasia and cognition? | 6.360 | 6.588 | 7.250 | **6.438** |
| 21 | In extremely preterm infants (< 28 weeks) do elective caesarean sections or vaginal deliveries result in better survival; brain injury and cognition? | 6.203 | 6.773 | 8.400 | **6.436** |
| 22 | If a mother is in preterm labour and expected to deliver imminently does administering a second dose of antenatal steroid early improve survival and bronchopulmonary dysplasia compared to standard care (not administering a second dose until the standard time period)? | 6.289 | 6.765 | 7.200 | **6.418** |
| 23 | In extremely preterm infants < 28 weeks does routine high frequency oscillatory ventilation (HFOV) improve survival; cognition and bronchopulmonary dysplasia when compared to standard ventilation? | 6.316 | 6.588 | 7.250 | **6.402** |
| 24 | In extremely preterm babies does restrictive total fluid (60; 90; 120; 150ml/kg/day) lead to improved survival and bronchopulmonary dysplasia when compared to liberal total fluid (90; 120; 150; 180; 200ml/kg/day)? | 6.360 | 6.333 | 6.000 | **6.344** |
| 25 | In extremely preterm infants does maintaining a midline head position for the first 72 hours of life improve survival and brain injury when compared to standard care? | 6.014 | 7.400 | 6.750 | **6.327** |
| 26 | In preterm babies who develop hyperglycaemia (>12mmol/L) should we treat with an insulin infusion or reduce the glucose infusion rate; to maximise growth and long term metabolic outcomes? | 6.373 | 6.316 | 5.250 | **6.316** |
| 27 | In preterm infants with echocardiographically confirmed persistent pulmonary hypertension of the newborn (PPHN) does inhaled nitric oxide improve survival; bronchopulmonary dysplasia and brain injury compared to no treatment? | 6.211 | 6.688 | 7.000 | **6.316** |
| 28 | In extremely preterm infants does on-demand haemodynamic assessment guided choice of inotrope therapy improve survival and other core outcomes compared to standard unit protocols? | 6.387 | 6.000 | 5.667 | **6.311** |

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| 29 | In babies diagnosed with gastro-oesophageal reflux does the use of anti-reflux medications improve outcomes such as bronchopulmonary dysplasia; sepsis and quality of life when compared with non-pharmacological support? | 6.107 | 6.750 | 7.200 | **6.308** |
| 30 | In preterm babies showing feeding cues whilst on non-invasive respiratory support; does commencing oral feeding (compared to waiting) improve outcomes such as breastfeeding rates; oral aversion and reflux? | 6.027 | 7.080 | 6.500 | **6.302** |
| 31 | Does point of care ultrasound guided umbilical venous catheter (UVC) position adjustments reduce workload; X-ray exposure and adverse events compared to standard X-ray guided UVC position adjustments? | 6.280 | 6.385 | 6.000 | **6.289** |
| 32 | In preterm babies do high nutrient enteral/ parenteral nutrition strategies (macronutrients at upper end of recommended intakes) improve core neonatal outcomes when compared with lower nutrient enteral/ parenteral nutrition strategies (macronutrients at lower levels of recommended intakes) without adverse events? | 6.329 | 5.950 | 7.000 | **6.280** |
| 33 | Does increased staffing with dedicated allied health professionals or care support workers to support parents with caring for their baby improve quality of life; length of stay and parental wellbeing over standard staffing? | 5.622 | 7.875 | 8.000 | **6.279** |
| 34 | In preterm babies requiring parenteral nutrition; does early parenteral nutrition within 8 hours of birth improve survival and neurodevelopmental outcomes when compared to late parenteral nutrition after 48 hours of life? | 6.053 | 6.667 | 7.800 | **6.265** |
| 35 | In preterm infants does prophylactic hydrocortisone treatment from day 1 to 10 improve survival and other core neonatal outcomes compared to a placebo? | 6.184 | 6.188 | 6.500 | **6.198** |
| 36 | In ex-preterm babies with inguinal hernias; does repair prior to discharge improve adverse events such as incarceration; when compared with repair after discharge? | 6.187 | 6.267 | 6.000 | **6.191** |
| 37 | In extremely preterm infants should structured blood pressure management be aiming for a target of greater than 30mmHg or greater than gestational age; to improve survival and brain injury? | 6.080 | 6.563 | 6.333 | **6.170** |
| 38 | In preterm infants does starting treatment with early probiotics (<24 hours of birth) versus later probiotics (when tolerating trophic feeds) reduce risk of necrotising enterocolitis; sepsis; dysbiosis? | 5.960 | 6.739 | 6.333 | **6.154** |

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| 39 | Does being born on a facilitative unit that promotes family centered care improve neurodevelopmental outcomes; length of stay and readmissions compared with traditional neonatal care? | 5.575 | 7.480 | 7.600 | **6.136** |
| 40 | In preterm babies does an embedded feeding team (comprising SALT; feeding advisor and dietetics) improve growth; breast-feeding rates; readmissions and parent-infant bonding as compared with standard care? | 5.600 | 7.625 | 6.800 | **6.125** |
| 41 | In moderately preterm infants (32-27 weeks) does immediate kangaroo mother care/ skin-to-skin for a minimum period of time per day improve breast-feeding rates; hypoglycaemia and autism spectrum disorders compared with standard care? | 5.649 | 7.440 | 6.333 | **6.114** |
| 42 | In all infants with cardiovascular instability; does access to targeted functional echocardiography improve outcomes such as survival; brain injury and kidney injury compared to standard care? | 5.960 | 6.313 | 7.000 | **6.053** |
| 43 | In all babies requiring admission to NICU at birth; does a delivery room cuddle with the parents improve survival; parental mental health and breast milk production when compared with no delivery room cuddle? | 5.493 | 7.400 | 7.333 | **6.047** |
| 44 | In babies with oesophageal atresia does routine placement of a transanastomotic tube (TAT) improve strictures; need for dilatations and need for rescue feeding method; when compared with no TAT placement? | 5.899 | 6.615 | 6.333 | **6.023** |
| 45 | In term babies over 48 hours of life; is a blood glucose threshold of 2.6mmol/L non-inferior to a blood glucose threshold of 3.0mmol/L for adverse events; cognition and breastfeeding rates? | 5.947 | 6.438 | 4.000 | **5.968** |
| 46 | In term babies receiving therapeutic hypothermia (cooling) does early parenteral nutrition improve survival and cognition when compared to only commencing parenteral nutrition after one week if feeds cannot be established? | 5.671 | 6.591 | 7.500 | **5.941** |
| 47 | In infants < 32 weeks gestation with patent ductus arteriosus (PDA) does artificial closure (ligation or medical) improve survival and bronchopulmonary dysplasia compared with supportive management only? | 5.747 | 6.529 | 6.500 | **5.917** |
| 48 | In all babies admitted to NICU; does a routine clinical psychologist assessment and ongoing support with weekly parent groups improve long term neonatal outcomes and parental mental health; compared to no psychology interventions? | 5.486 | 7.040 | 5.667 | **5.867** |

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| 49 | In infants requiring higher level care does being delivered at a level three NICU improve survival; bronchopulmonary dysplasia and adverse events in comparison to postnatal transfer from a different unit? | 5.467 | 6.792 | 7.167 | **5.867** |
| 50 | In preterm infants; does adopting a 'golden hour' approach completing all procedures within one hour of birth improve survival; BPD and cognition when compared to standard care? | 5.413 | 7.235 | 7.800 | **5.856** |
| | **Round 2** | | | | |
| 51 | Does the support of a dedicated specialist lactation consultant on NICU from admission to discharge improve growth; breast-milk feeding and maternal mental health? | 5.751 | 6.676 | 6.889 | **6.080** |
| 52 | In extremely preterm infants who received a dose of surfactant at birth do repeated doses of surfactant at 48 and 72 hours improve survival and bronchopulmonary dysplasia when compared to standard care? | 5.812 | 6.500 | 7.813 | **6.078** |
| 53 | For all infants requiring neonatal care does a formal multi-disciplinary discharge pathway with nationally approval parental information and tailored education sessions reduce readmission; A&E attendances and improve parental wellbeing compared to standard local discharge pathways? | 5.467 | 7.100 | 7.294 | **6.075** |
| 54 | Does supplementation with breast milk fortifier after discharge or term age improve growth; breast-feeding rates and long term outcomes in preterm babies? | 5.909 | 6.418 | 6.111 | **6.054** |
| 55 | Does the use of loperamide post stoma formation improve parenteral nutrition related liver disease; line sepsis and length of stay when compared to placebo? | 5.968 | 6.000 | 7.500 | **6.049** |
| 56 | In babies diagnosed with necrotising enterocolitis does remote ischaemic condition improve survival; necrotising enterocolitis and duration of parenteral nutrition compared to standard care? | 5.808 | 6.600 | 7.091 | **6.043** |
| 57 | Does a psychology intervention supporting staff with regular reflective practice and psychoeducation improve staff sickness; staff retention and staff mental health issues compared to no psychological intervention for staff? | 5.570 | 7.014 | 6.118 | **6.042** |
| 58 | In preterm infants receiving less invasive surfactant administration does use of pharmacological methods alongside environmental measures improve success rates and comfort when compared to environmental measures alone (swaddling/ sucrose)? | 5.868 | 6.288 | 6.556 | **6.004** |

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| 59 | In preterm babies receiving donor milk due to insufficient mothers milk; is it superior to switch to preterm formula once on full feeds or wait until term corrected gestational age? | 5.885 | 6.254 | 6.125 | **5.996** |
| 60 | In preterm babies with chronic lung disease does extending caffeine therapy until term (rather than standard care of discontinuing around 34 weeks corrected gestation) improve survival and cognition? | 5.783 | 6.077 | 7.889 | **5.992** |
| 61 | In preterm babies requiring parenteral nutrition does higher range lipid (fats) intake or lower range lipid (fats) intake improve growth and long term metabolic outcomes? | 6.097 | 5.827 | 5.231 | **5.987** |
| 62 | In preterm infants does high dose vitamin D supplementation (>800 units) improve metabolic bone disease when compared to low dose vitamin D supplementation (< 400 units)? | 5.981 | 6.000 | 5.909 | **5.982** |
| 63 | In preterm babies whose mothers would like to establish exclusive breast-feeding; does exposure to routine bottle feeding reduce breast-feeding success compared to exposure to routine nasogastric feeding? | 5.661 | 6.565 | 6.611 | **5.969** |
| 64 | Does dopamine vs adrenaline use for hypotension in preterm infants result in improved survival; neurodevelopemental outcome at 24 months corrected age and reduced morbidity (such as necrotising enterocolitis and bronchopulmonary dysplasia) | 5.847 | 6.000 | 7.750 | **5.957** |
| 65 | Does follow up of moderate to late preterm infants to 5 years improve school age outcomes and health? | 5.486 | 6.800 | 7.000 | **5.953** |
| 66 | In neonates with meconium ileus and obstruction or post-laparotomy with obstruction; does saline or N-acetylcysteine treatment improve speed of establishing feeds or reduce the need for subsequent laparotomy when compared to supportive care? | 5.952 | 6.154 | 5.333 | **5.940** |
| 67 | In preterm infants with established chronic lung disease on invasive/non-invasive respiratory support at term corrected does a weaning course of prednisolone and azithromycin prophlyaxis improve home oxygen use and duration; readmissions with respiratory illnesses and length of stay? | 5.872 | 5.956 | 6.818 | **5.932** |
| 68 | Does the use of a respiratory function monitor to guide tidal volumes at birth reduce short-term need for ventilation and long-term outcomes of bronchopulmonary dysplasia; brain injury and 2 year outcomes? | 5.764 | 6.000 | 7.667 | **5.929** |

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| 69 | In extremely preterm infants < 28 weeks is assist control ventilation (with volume targeting) superior to SIMV (with volume targeting) with regards to survival; ventilation days and bronchopulmonary dysplasia? | 5.795 | 6.105 | 7.000 | **5.928** |
| 70 | In babies diagnosed with NEC does treatment with pentoxifylline improve survival; duration of PN and brain injury compared to standard care? | 5.795 | 6.105 | 7.091 | **5.928** |
| 71 | In preterm babies does targeting higher oxygen saturations of 92-97% lead to improved survival without complications such as NEC (when compared to standard care? | 5.647 | 6.113 | 8.111 | **5.918** |
| 72 | Does providing ongoing psychology support in the community as part of the routine discharge package improve quality of life; bonding and parental mental health compared to routine discharge with no psychology follow-up? | 5.204 | 7.042 | 7.316 | **5.914** |
| 73 | In term babies admitted to NICU for respiratory support would lowering the target saturations range to > 90% (rather than standard target) improve length of stay and duration of respiratory support without increasing adverse outcomes? | 5.769 | 5.980 | 7.235 | **5.911** |
| 74 | In extremely preterm infants with patent ductus arteriosus on a screening echocardiogram does early medical treatment (< 7 days) improve core neonatal outcomes compared with no treatment? | 5.755 | 6.205 | 6.538 | **5.891** |
| 75 | In preterm babies < 32 weeks with an oxygen requirement of over 40% does routine intubation and ventilation improve survival and bronchopulmonary dysplasia when compared to intubation based solely on clinical indications such as apnoea? | 5.639 | 6.255 | 7.353 | **5.877** |
| 76 | Does providing a bespoke psychological intervention to parents who witnessed a serious incident (either for their own or a different baby) improve parental trauma scores; parental mental health and quality of life compared to not providing bespoke support? | 5.187 | 6.931 | 7.316 | **5.876** |
| 77 | Does education for health professionals about the support needs of ethnically diverse families reduce increased neonatal mortality risk; when compared to standard staff training? | 5.229 | 6.839 | 7.750 | **5.872** |
| 78 | Does a weekly ‘allied health professional’ ward round with parents present improve parental satisfaction; when compared to allied health professional ward rounds without parental presence? | 5.200 | 6.904 | 7.500 | **5.861** |

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| 79 | In babies with seizures does maintenance topiramate improve seizure control and brain injury when compared to phenobarbitone? | 5.716 | 6.306 | 6.273 | **5.851** |
| 80 | In extremely preterm infants with respiratory distress requiring surfactant administration is elective intubation and ventilation preferable to less-invasive-surfactant-administration to improve pneumothorax rates and bronchopulmonary dysplasia? | 5.696 | 6.395 | 5.933 | **5.837** |
| 81 | In babies on the NICU; do parent-led ward rounds improve quality of life; parental mental health and breast-feeding rates in comparison to standard clinician led ward rounds? | 5.207 | 6.819 | 7.053 | **5.834** |
| 82 | In babies with respiratory distress syndrome should a second dose of surfactant be given at 30% or 40% to improve bronchopulmonary dysplasia rates and other core neonatal outcomes? | 5.740 | 5.750 | 7.400 | **5.827** |
| 83 | Do preterm infants have lower scores on standardised Speech and Language scales at 18 months; 3 years and 5 years compared to term born infants demonstrating the need for fully funded; robust speech and language services at neonatal discharge? | 5.331 | 6.403 | 7.625 | **5.808** |
| 84 | In extremely preterm infants that are ventilator dependent on day 8 of life does a treatment course of nebulised budesonide as compared to placebo improve survival; bronchopulmonary dysplasia; and length of stay? | 5.614 | 6.071 | 7.600 | **5.798** |
| 85 | In babies born pre-term; who have bronchopulmonary dysplasia; does a standardised ventilation weaning plan improve duration of ventilation; length of hospital stay; growth; quality of life and neurodevelopmental outcomes at 12 and 24 months? | 5.597 | 6.150 | 7.200 | **5.794** |
| 86 | In babies with suspected hypoxic ischaemic encephalopathy in level 2 neonatal units; does the use of telemedicine to aid diagnosis improve long-term neurodevelopmental outcomes? | 5.366 | 6.565 | 7.333 | **5.760** |
| 87 | In very preterm infants at delivery does setting initial FiO2 at 0.6 versus 0.3 and targeting oxygen saturations of 80-85% at 5 mins and 85-95% at 10 mins or later increase survival without disability? | 5.577 | 5.941 | 8.000 | **5.725** |
| 88 | For parents of preterm infants does delivering detailed information of future health risks at discharge; improve quality of life; parental satisfaction and | 5.099 | 6.300 | 7.375 | **5.596** |

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| | parental mental health; when compared to providing it at a later timepoint (for example 12 months corrected age)? | | | | |
| 89 | In babies diagnosed antenatally with congenital diaphragmatic hernia; does the use of intranasal sedation for intubation at delivery; compared to no sedation lead to fewer intubation attempts; better cardiorespiratory stability and improved long term neurodevelopmental outcomes? | 5.423 | 6.286 | 6.250 | **5.596** |
| 90 | In preterm infants born at <28w gestation does regular screening for Ureaplasma colonisation and treatment where indicated; improve outcomes (bronchopulmonary dysplasia; length of stay)? | 5.580 | 5.300 | 5.250 | **5.530** |
| 91 | Does a structured package of malnutrition investigations improve outcomes such as nutritional deficiences; growth and core long-term outcomes? | 5.211 | 5.792 | 7.500 | **5.525** |
| 92 | In all babies requiring intubation; does the nasal route offer an acceptable alternative that results in fewer unplanned extubations? | 5.356 | 5.500 | 6.667 | **5.465** |
| 93 | In all infants (including preterm infants) with suspected hypoxic ischaemic encephalopathy; does intervention with therapeutic hypothermia (cooling) affect visual development; when compared to standard care? | 4.814 | 6.409 | 7.667 | **5.347** |
| 94 | Does a smoking cessation support package delivered in NICU by NICU staff reduce parental smoking relapse rates by 12 months post discharge? | 4.986 | 5.500 | 6.000 | **5.192** |

**Lower Prioritised Questions**

| **Rank** | **Question** | **Doctors/ Researchers** | **Nurses/ AHPs** | **Parents/ Former Patients** | **Mean Score** |
|---|---|---|---|---|---|
| 95 | Does regular ultrasound monitoring of umbilical lines to identify associated thrombus improve core neonatal outcomes? | 4.861 | 5.000 | 5.200 | **4.905** |
| 96 | Do breastfeeding preterm infants who receive routine daily vitamin K supplementation post-discharge have lower prevalence of vitamin K deficiency in infancy? | 4.319 | 5.038 | 5.714 | **4.590** |

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| 97 | For all babies requiring neonatal care; does a formal nursing training package on length measurement improve reliability and validity of measurements when compared to standard care? | 3.771 | 5.267 | 5.800 | **4.295** |
| | **Round 1** | | | | |
| 98 | Does referral to early intervention occupational therapy at the point of neonatal discharge improve cognition; quality of life and social-emotional outcomes at school age; compared to no routine occupational therapy referral? | 5.539 | 6.500 | 7.222 | **5.968** |
| 99 | In babies undergoing therapeutic hypothermia does midazolam sedation rather than standard care with morphine sedation improve brain injury and cognition? | 5.723 | 6.556 | 6.500 | **5.968** |
| 100 | Does dedicated physiotherapy support after discharge improve parental and infant mental health; compared to no physiotherapy support? | 5.544 | 6.556 | 6.500 | **5.966** |
| 101 | In extremely preterm infants that are ventilator dependent on day 8 of life and likely to need pressure support ventilation at 36 weeks corrected gestation does a treatment course of hydrocortisone; as compared to a treatment course of dexamethasone improve survival and bronchopulmonary dysplasia? | 5.832 | 6.083 | 6.778 | **5.940** |
| 102 | In babies diagnosed with necrotising enterocolitis does therapeutic hypothermia improve survival and brain injury when compared to standard care? | 5.667 | 6.733 | 7.000 | **5.939** |
| 103 | In extremely preterm infants does limiting routine physical examination to times of clinical/parental or nursing concerns improve survival and complications of prematurity when compared to daily routine examination on ward rounds? | 5.583 | 6.767 | 6.571 | **5.934** |
| 104 | In preterm infants with respiratory distress syndrome requiring surfactant therapy is the best mode of delivery an iGel or a less-invasive-surfactant-administration catheter to improve success rates and mechanical ventilation rates? | 5.879 | 6.083 | 5.900 | **5.917** |
| 105 | In preterm babies receiving nasogastric feeds; does routinely aspirating compared to not routinely aspirating improve time to full enteral feeds; growth and length of stay without adverse events? | 6.104 | 5.417 | 5.600 | **5.894** |

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| 106 | When accessing lines does a sterile aseptic technique improve survival and sepsis over an aseptic non-touch technique? | 5.819 | 5.818 | 6.750 | **5.885** |
| 107 | Does a staff and parental training package on psychologically informed environments; trauma-informed care and compassion focused approaches improve core neonatal outcomes and parental mental health? | 5.077 | 7.077 | 7.364 | **5.883** |
| 108 | In infants with chronic lung disease does diuretic therapy improve home oxygen rates and neurodevelopmental outcomes when compared to no diuretics? | 5.653 | 6.077 | 7.500 | **5.869** |
| 109 | In preterm babies requiring parenteral nutrition does higher range energy (calorie) intake or lower range energy (calorie) intake improve growth and long term metabolic outcomes? | 5.854 | 5.867 | 6.000 | **5.865** |
| 110 | In all babies admitted to NICU; does a dedicated education training package covering unit familiarisation & protocols; parenting issues; financial support and bonding improve parental mental health alongside long-term neonatal outcomes; when compared to standard care? | 5.434 | 6.410 | 6.818 | **5.857** |
| 111 | In preterm babies does targeting tight control of weight gain along birth centile using calorific interventions improve outcomes when compared to allowing growth trajectory below birth centile (as per standard growth using population data)? | 6.031 | 5.500 | 5.375 | **5.852** |
| 112 | In all infants characterised as having circulatory failure; does the use of certain biomarkers improve survival and brain injury when compared to standard monitoring using blood pressure? | 5.663 | 6.381 | 6.429 | **5.847** |
| 113 | Does access to specialist neonatal respiratory physiotherapy (percussion/ treatment techniques) compared to neonatal staff training on physiotherapy techniques improve adverse events and neonatal outcomes? | 5.440 | 6.381 | 6.429 | **5.824** |
| 114 | In invasively ventilated extremely preterm infants is extubation to synchronised non-invasive positive pressure ventilation (NIPPV) or non-synchronised NIPPV superior when considering extubation success; survival and bronchopulmonary dysplasia? | 5.535 | 6.423 | 7.222 | **5.816** |
| 115 | Does targeted screening and needs assessment of social determinants (housing; safety; mental health; parental health literacy; transport needs; | 5.597 | 6.237 | 5.556 | **5.790** |

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| | food security; community support) improve survival; quality of life and adverse events? | | | | |
| 116 | In extremely preterm babies < 28 weeks is the use of neurally adjusted ventilatory assist (NAVA) ventilation with extubation to non-invasive NAVA (NIV NAVA) superior to conventional ventilation with extubation to NIPPV/ CPAP with regards to extubation success and bronchopulmonary dysplasia? | 5.593 | 6.333 | 6.333 | **5.770** |
| 117 | In preterm babies does sling provision and education to facilitate skin-to-skin contact improve parental wellbeing and weight gain when compared to standard care? | 5.276 | 6.590 | 6.200 | **5.760** |
| 118 | In extremely preterm infants with established chronic lung disease at 36 weeks corrected age; does sildenafil treatment improve survival compared with a placebo? | 5.748 | 5.696 | 6.000 | **5.756** |
| 119 | In preterm babies requiring parenteral nutrition does high amino acid intake improve growth and long term metabolic outcomes compared to standard intake? | 5.807 | 5.724 | 5.143 | **5.750** |
| 120 | Does implementation of formal parent peer support with meetings; social media and one-to-one peer support improve length of stay; readmissions and parental mental health compared to informal parental peer support? | 5.289 | 6.500 | 6.300 | **5.742** |
| 121 | In ex-preterm babies discharged home; does a community based sensory processing workshop improve infant regulation; improve bonding and decrease autism spectrum disorders compared to routine care? | 5.342 | 6.378 | 6.444 | **5.738** |
| 122 | For subsequent pregnancies after a neonatal admission; would a dedicated antenatal counselling and support programme improved parental anxiety and neonatal outcomes compared to no support programme? | 5.163 | 6.447 | 7.600 | **5.734** |
| 123 | In all infants receiving invasive or non-invasive respiratory support does prone or supine positioning improve the number of ventilation days and duration of supplemental oxygen? | 5.327 | 6.067 | 8.000 | **5.690** |
| 124 | Does an occupational therapist led parental training session and ongoing support regarding reading infant cues and participation in caregiving improve bonding and parental confidence compared to standard parental support? | 5.039 | 6.667 | 6.778 | **5.672** |

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| 125 | In preterm infants at risk of necrotising enterocolitis does treatment with gut-derived IFN-y-releasing CD4+ T cells improve survival; brain injury and quality of life when compared to current practice? | 5.403 | 6.875 | 6.833 | **5.671** |
| 126 | In babies requiring long term parenteral nutrition (PN); does supporting an earlier discharge home (when stable PN established) compared to standard care improve quality of life for families without increased risk? | 5.333 | 6.147 | 7.125 | **5.667** |
| 127 | In term infants with congenital diaphragmatic hernia is extracorporeal membrane oxygenation (ECMO) or high-frequency oscillatory ventilation (HFOV) superior to improve survival; brain injury and quality of life? | 5.358 | 6.360 | 7.125 | **5.664** |
| 128 | In preterm babies requiring parenteral nutrition does high vitamin D intake improve growth and long-term metabolic outcomes compared to standard intake? | 5.678 | 5.655 | 5.375 | **5.653** |
| 129 | In formula fed babies born moderately preterm at 34 to 37 weeks gestation does enhanced nutrition support improve growth and long term cognition; when compared to term formula? | 5.547 | 5.821 | 6.000 | **5.650** |
| 130 | Do regular occupational therapy interventions for all babies admitted to NICU improve cognition; adverse events and decrease sensory processing disorders in comparison to minimal (<1 day per week) occupational therapy input? | 5.218 | 6.275 | 6.556 | **5.646** |
| 131 | In all babies does next generation whole genome sequencing improve the diagnostic/prognostic yield compared to current newborn screening practices without adverse ethical issues? | 5.622 | 5.333 | 6.625 | **5.640** |
| 132 | Does an occupational therapist led staff training session about sensitive neonatal handling improve long term outcomes such as sensory processing disorders and improve staff-parent relationships; compared to standard staff training? | 5.053 | 6.590 | 6.200 | **5.629** |
| 133 | Does circadian rhythm entrainment with nocturnal melatonin improve survival and neurodevelopmental impairment in infants at high risk for neurological injury (preterm < 28 weeks with peri-ventricular leukomalacia/ grade 3/4 intra-ventricular haemorrhage or term babies with hypoxic ischaemic encephalopathy) when compared to placebo? | 5.506 | 5.739 | 6.571 | **5.624** |

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| 134 | In ex-preterm infants is early or late weaning on solids preferable with regards to growth; feeding behaviours and allergy? | 5.284 | 6.079 | 6.500 | **5.580** |
| 135 | In all babies requiring pre-medications for intubation is propofol or fentanyl / suxamethonium superior in improving survival and bronchopulmonary dysplasia? | 5.412 | 5.720 | 6.900 | **5.577** |
| 136 | In extremely preterm babies in the delivery room; does oxygen targeting based on near infrared spectroscopy (NIRS) (rather than SpO2) lead to improved survival and other core neonatal outcomes? | 5.265 | 6.320 | 7.167 | **5.558** |
| 137 | For parents of preterm infants does detailed information about future health risks (stroke; high blood pressure and heart disease) improve quality of life; parental satisfaction and parental mental health compared to no information? | 5.193 | 6.115 | 7.714 | **5.552** |
| 138 | Does provision of regular neonatal occupational therapy improve parental and staff perceptions of the developmental benefits for high-risk infants; compared to minimal occupational therapy input? | 5.013 | 6.325 | 6.500 | **5.543** |
| 139 | In preterm babies requiring parenteral nutrition do lower energy:protein ratios improve growth and long term metabolic outcomes compared to standard ratios? | 5.570 | 5.552 | 5.143 | **5.541** |
| 140 | In babies born as part of multiple births what is the effect of separation at any part of the neonatal journey on cognition; quality of life and adverse events? | 4.671 | 6.718 | 7.778 | **5.540** |
| 141 | When considering stopping antibiotics on the NNU; does the use of procalcitonin reduce the duration of antibiotics courses without adverse events compared to standard management using C-reactive protein? | 5.647 | 5.067 | 5.250 | **5.537** |
| 142 | In all babies being treated for sepsis do continuous vancomycin infusions increase survival and sepsis when compared to traditional multiple daily dose regimens? | 5.463 | 5.400 | 6.667 | **5.525** |
| 143 | Is plasmalyte or sodium chloride a better choice of bolus fluid for preterm infants with presumed hypovolaemia or poor perfusion? | 5.412 | 6.200 | 5.400 | **5.524** |
| 144 | Does a necrotising enterocolitis scoring tool incorporating parental views improve survival; sepsis and necrotising enterocolitis compared to necrotising enterocolitis scoring tools incorporating only professional views? | 5.092 | 6.682 | 6.375 | **5.519** |

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| 145 | In preterm infants does the use of freshly expressed maternal milk a couple of times a day (as opposed to standard care with frozen or refrigerated maternal milk) improve growth and long term neonatal outcomes? | 5.351 | 5.561 | 6.600 | **5.497** |
| 146 | In all preterm babies < 32 weeks does nasal intubation rather than oral intubation improve feeding problems at 3 months corrected age? | 5.010 | 6.545 | 6.800 | **5.479** |
| 147 | Does parental presence during handovers improve parental satisfaction without increasing handover duration; compared to parents being asked to step outside? | 4.831 | 6.282 | 7.300 | **5.476** |
| 148 | In infants requiring sedation during ventilation does dexmedetomidine improve cognition and quality of life compared to standard care with an opiate infusion? | 5.263 | 6.000 | 6.143 | **5.471** |
| 149 | In babies on the postnatal ward receiving IV antibiotics for risk factors with a raised C-reactive protein; does performing a lumbar puncture (compared to not performing a lumbar puncture) lead to prolonged duration of stay or any adverse events? | 5.274 | 5.875 | 6.429 | **5.470** |
| 150 | In babies transferred between different NICUs does a psychologist supported 'repatriation' training package for parents improve parental mental health? | 4.909 | 6.436 | 6.000 | **5.468** |
| 151 | In preterm babies requiring parenteral nutrition does high vitamin A intake improve growth and long-term metabolic outcomes compared to standard intake? | 5.437 | 5.621 | 5.250 | **5.468** |
| 152 | Does giving an extra dose of caffeine prior to planned extubation or within 2 hours of unplanned extubation increase extubation success (remaining extubated at 5 days) compared to standard caffeine therapy? | 5.163 | 5.889 | 6.833 | **5.441** |
| 153 | In extremely preterm infants does 30 minutes of daily conversation with a parent or caregiver improve cognition and quality of life compared with no dedicated conversation? | 4.865 | 6.154 | 6.778 | **5.418** |
| 154 | In infants at risk of hypoglycaemia on the postnatal ward; does the use of donor milk for feed supplementation (as opposed to standard care with formula or glucose gel) improve maternal breast-feeding rates; hypoglycaemia episodes and quality of life? | 5.053 | 5.821 | 7.333 | **5.406** |

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| 155 | Do tongue-tie interventions (laser or ligation) improve time taken to establish breast feeding; duration of breast feeding and parental satisfaction? | 5.242 | 5.605 | 6.100 | **5.399** |
| 156 | In preterm infants do routine clotting screens on admission (with corrections of derangements) lead to improve survival; brain injury and cognition compared to not performing a clotting screen unless clinically indicated? | 5.361 | 5.176 | 6.286 | **5.393** |
| 157 | In preterm babies does enteral insulin administration improve survival; sepsis and necrotising enterocolitis when compared to a masked placebo medication? | 5.494 | 4.769 | 6.125 | **5.380** |
| 158 | In babies with direct antiglobulin test (DAT) positive jaundice on the postnatal ward; does routine folic acid supplementation improve cognition; quality of life and adverse events? | 5.262 | 5.600 | 5.875 | **5.366** |
| 159 | In 28 to 32 week infants on non-invasive respiratory support is the best method to determine the need for surfactant administration lung ultrasound scoring or clinical signs/X-ray? | 5.257 | 5.560 | 5.900 | **5.360** |
| 160 | In preterm babies requiring parenteral nutrition does high folic acid intake improved growth and long-term metabolic outcomes compared to standard intake? | 5.291 | 5.552 | 5.250 | **5.350** |
| 161 | Would implementation of a 'buddy system' during the immediate postnatal period between neonatal and maternity staff looking after admitted babies and admitted mothers help to ensure parental presence at key neonatal aspects alongside managing maternal health; thus preventing early discharge and improving breast-milk production? | 4.842 | 6.105 | 6.111 | **5.325** |
| 162 | In preterm infants with suspected necrotising enterocolitis undergoing laparotomy does tranexamic acid improve survival and adverse events compared to no tranexamic acid treatment? | 5.118 | 5.750 | 6.333 | **5.296** |
| 163 | In preterm infants; does delivery and management in a 'newborn individualized developmental care and assessment programme (NIDCAP) certified unit improve cognition; length of stay and breast-feeding rates when compared to management in a non-NIDCAP certified unit? | 4.592 | 6.867 | 5.833 | **5.268** |
| 164 | Does zinc supplementation of preterm infants improve growth? | 5.266 | 5.032 | 5,889 | **5.254** |

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| 165 | In infants undergoing surgery does routine cerebral near infrared spectroscopy (NIRS) monitoring to target optimal analgesia improve cognition when compared to routine care? | 5.125 | 5.500 | 5.857 | **5.243** |
| 166 | In infants post-surgery does oxycodone analgesia reduce length of ventilation and length of hospital stay when compared to standard care with an opiate infusion? | 5.039 | 5.762 | 6.000 | **5.243** |
| 167 | How can 'memory-milk-gift-initiatives' best be implemented to support bereaved mothers with donating breast milk; and do these initiatives improve parental experiences and maternal mental health? | 4.852 | 5.675 | 6.900 | **5.239** |
| 168 | In infants who have been successfully intubated is ultrasound or X-ray the best method to confirm endotracheal tube tip position and avoid adverse events? | 5.118 | 5.240 | 6.100 | **5.212** |
| 169 | In babies diagnosed with brain injury; does specialist neonatal music therapy improve cognition; quality of life and short term physiological parameters when compared with standard neonatal care? | 4.766 | 5.838 | 6.300 | **5.210** |
| 170 | In preterm infants on the neonatal unit requiring respiratory support (invasive or non-invasive) does respiratory syncytial virus (RSV) prophylaxis improve survival and bronchopulmonary dysplasia compared to standard care (no RSV prophylaxis whilst an inpatient)? | 4.842 | 5.480 | 7.778 | **5.156** |
| 171 | Does a dedicated sibling support pack improve neonatal outcomes and family bonding; compared to no sibling support pack? | 4.481 | 6.237 | 5.818 | **5.127** |
| 172 | Do individualised infant diaries improve parental mental health and family bonding compared to no infant diary? | 4.675 | 5.872 | 5.667 | **5.120** |
| 173 | In clinically well term babies with > 10% weight loss does performing serum electrolyte measurements decrease survival; sepsis and seizures when compared to not measuring electrolytes? | 4.893 | 5.720 | 5.571 | **5.112** |
| 174 | In clinically well babies noted to have a raised cord lactate (but no TOBY criteria met) does observation and detailed clinical assessment lead to reduced length of stay and increased breast-feeding rates when compared to sequential blood gases with possible admission for intravenous fluids? | 5.024 | 5.474 | 5.000 | **5.103** |

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| 175 | In intubated preterm infants does a short course of diuretics prior to extubation improve bronchopulmonary dysplasia and cognition when compared to a placebo? | 4.901 | 5.400 | 5.778 | **5.052** |
| 176 | In term babies establishing breast-feeding on the post-natal ward; does the use of cup; syringe or spoon feeding increase the aspiration risk over bottles? | 4.872 | 5.308 | 5.700 | **5.049** |
| 177 | In infants born to mothers with a history of maternal thyrotoxicosis; does inpatient observations for 48 hours with follow-up thyroid blood tests on day 5 lead to improved survival; cognition and adverse events when compared to routine postnatal care with detailed safety net advice? | 5.123 | 4.941 | 4.333 | **5.048** |
| 178 | In preterm babies with hyperbilirubinaemia; does using specific phototherapy radiance improve survival; brain injury and cognition when compared to using maximal phototherapy treatment? | 4.707 | 5.900 | 6.143 | **5.018** |
| 179 | In babies receiving end of life care; does specialist neonatal music therapy improve quality of life; parental experience and bereavement support in comparison to standard end of life care? | 4.526 | 5.784 | 5.700 | **5.000** |
| 180 | In neonates requiring surgery does deferring surgery until bilirubin is below a certain clinical level improve wound healing; length of stay and readmission rates? | 4.743 | 5.784 | 5.700 | **4.989** |
| 181 | In unwell term infants admitted to the NICU; does the routine addition of anti-viral treatments improve survival and quality of life compared to standard treatment with antibiotics only? | 4.524 | 5.368 | 7.100 | **4.894** |
| 182 | In preterm babies does use of a fluidised positioning pillow from birth improve incidence of scaphocephaly or plagiocephaly at discharge? | 4.378 | 6.200 | 5.333 | **4.890** |
| 183 | In preterm infants with patent ductus arteriosus does treatment with indomethacin improve survival when compared to placebo treatment? | 4.682 | 5.647 | 5.167 | **4.861** |
| 184 | In neonates post-surgery does giving prophylactic antibiotics only if there is a left shift on the differential white blood cell count improve survival; sepsis and adverse events compared with no antibiotics? | 4.354 | 5.188 | 5.500 | **4.554** |
| 185 | Does routinely sending the endotracheal tube tip for microscopy, culture and sensitivity after extubation increase survival and sepsis? | 3.904 | 4.500 | 5.857 | **4.130** |

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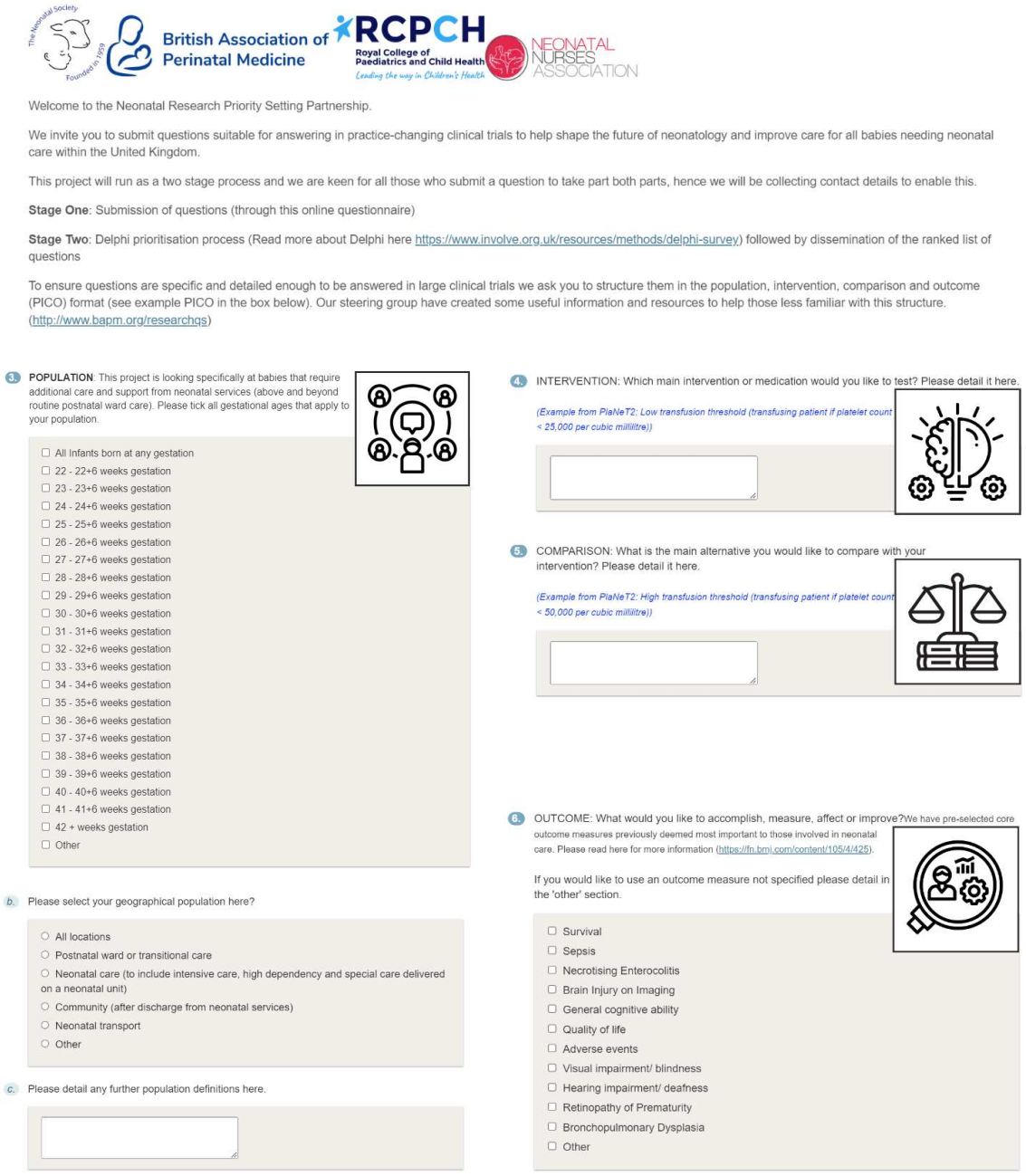
| 186 | In preterm babies does taking a bath on the neonatal unit prior to discharge increase the risk of respiratory infections or other adverse events; when compared with no bath? | 3.623 | 4.568 | 4.778 | **3.992** |

**Online supplementary eText 1:** Members of the Neonatal Priority Setting Partnership Steering Group.

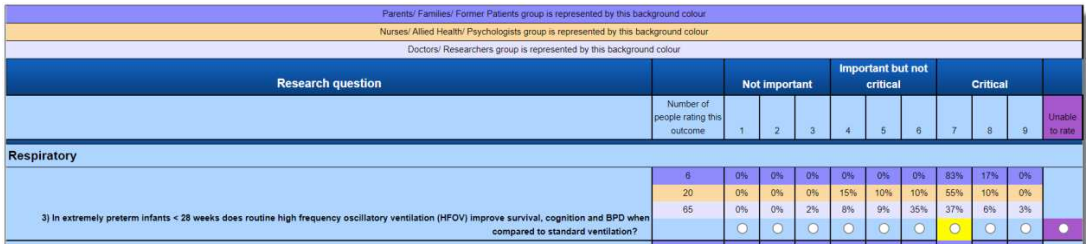
| **Steering Group Member** | **Role and affiliation** |
|---|---|
| Cheryl Battersby (CB) | Academic Neonatologist, British Association of Perinatal Medicine (BAPM) Data/Informatics lead & member of NIHR prioritisation committee. |
| James Boardman (JPB) | Professor of Neonatal Medicine and immediate past president of the Neonatal Society. |
| Elaine Boyle (EB) | Professor of Neonatal Medicine and Chair of the National Institute for Health Research Neonatal Clinical Studies Group. |
| William Carroll (WC) | Consultant Paediatrician and Royal College of Paediatrics and Child Health (RCPCH) officer for Research. |
| Jon Dorling (JD) | Professor of Paediatrics, Neonatal Consultant and BAPM research lead. |
| Kate Dinwiddy (KD) | Chief Executive of BAPM. |
| Katie Evans (KE) | Project Co-ordinator and Honorary Clinical Research Fellow in Neonatal Medicine. |
| Chris Gale (CG) | Professor of Neonatal Medicine and Neonatal Society Meeting Secretary. |
| Katie Gallagher (KG) | Academic Neonatal Nurse and Neonatal Nurses Association representative. |
| Pollyanna Hardy (PH) | Clinical Trials Statistician and Director of National Perinatal Epidemiology Unit Clinical Trials Unit. |
| Emma Johnston (EJ) | Parent representative and Parents and Family engagement Lead with the Thames Valley and Wessex Operational Delivery Network. |
| Helen Mactier (HM) | Consultant Neonatologist, Honorary Clinical Associate Professor and immediate past president of BAPM. |
| Claire Marcroft (CM) | Neonatal Physiotherapist and Allied Health Professionals Representative. |
| James Webbe (JW) | Trainee representative and Neonatal Medicine Trainee. |

**Online Supplementary eFigure 1:** Question submission software designed to support participants with submission of research questions in a population, intervention, comparison, outcome (PICO) structure.



**Online Supplementary eFigure 2:** Example of Round 3 eDelphi view.

Different Stakeholder Groups average rankings were colour coded (Purple for parents/ former patients, Orange for nurses/ allied healthcare and grey for doctors/ researchers) . This was explained to participants in the key above each speciality domain and also in the introductory paragraph of the priority setting exercise.



Parents/ Families/ Former Patients group is represented by this background colour

Nurses/ Allied Health/ Psychologists group is represented by this background colour

Doctors/ Researchers group is represented by this background colour

| Research question | | Not important | | | Important but not critical | | | Critical | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Number of people rating this outcome | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Unable to rate |
| **Respiratory** | | | | | | | | | | | |
| | 6 | 0% | 0% | 0% | 0% | 0% | 0% | 83% | 17% | 0% | |
| | 20 | 0% | 0% | 0% | 15% | 10% | 10% | 55% | 10% | 0% | |
| | 65 | 0% | 0% | 2% | 8% | 9% | 35% | 37% | 6% | 3% | |
| 3) In extremely preterm infants < 28 weeks does routine high frequency oscillatory ventilation (HFOV) improve survival, cognition and BPD when compared to standard ventilation? | | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ● |

Bronchopulmonary Dysplasia (BPD)

**Online Supplementary eText 2:** Full list of prioritised research questions.

Final mean scores displayed by individual stakeholder groups alongside final mean scores.

## Highly Prioritised Questions

| Rank | Question | Doctors/ Researchers | Nurses/ AHPs | Parents/ Former Patients | Mean Score |
|---|---|---|---|---|---|
| | **Round 3** | | | | |
| 1 | Does routine fortification of human milk feeds improve necrotising enterocolitis and long-term neurodevelopmental outcomes in preterm babies? | 7.187 | 7.542 | 7.833 | **7.305** |
| 2 | In preterm and term babies requiring resuscitation; does intact cord resuscitation improve survival and brain injury compared to standard resuscitation with early cord clamping? | 6.987 | 6.882 | 7.333 | **6.990** |
| 3 | In babies diagnosed with necrotising enterocolitis does earlier surgical intervention improve survival; brain injury and quality of life compared to standard practice? | 6.867 | 7.000 | 8.200 | **6.959** |
| 4 | Does therapeutic hypothermia (cooling) improve brain injury and general cognition in babies with mild hypoxic ischaemic encephalopathy (HIE) compared to standard care? | 6.763 | 7.474 | 7.200 | **6.920** |
| 5 | In extremely preterm infants < 28 weeks should we routinely use non-invasive positive pressure ventilation (NIPPV) or continuous positive airway pressure (CPAP) as the primary mode of respiratory support to improve survival and reduce bronchopulmonary dysplasia (BPD)? | 6.842 | 7.000 | 6.800 | **6.867** |
| 6 | Is early breastmilk fortification or late breastmilk fortification superior with regards to outcomes such as necrotising enterocolitis in preterm babies? | 6.767 | 7.458 | 5.822 | **6.857** |
| 7 | In preterm babies do probiotics improve survival; sepsis and necrotising enterocolitis? | 6.627 | 7.125 | 8.333 | **6.838** |
| 8 | Does human-derived milk fortifier rather than bovine-derived milk fortifier improve outcomes such as necrotising enterocolitis in preterm babies? | 6.587 | 7.500 | 7.333 | **6.838** |
| 9 | In very preterm infants at delivery does physiological based cord clamping (i.e. stabilisation or resuscitation with the cord intact and only clamping when heart | 6.600 | 6.824 | 7.833 | **6.714** |

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| | rate is> 100 beats per minute and oxygen saturation >85% in FiO2 <0.4) versus time-based clamping at 60 seconds (or earlier if stabilisation or resuscitation is needed) increase survival without disability? | | | | |
| 10 | In preterm infants with insufficient maternal milk available; does the use of pasturised human milk (donor) as compared with preterm formula reduce necrotising enterocolitis requiring surgery and improve two-year neurodevelopmental outcomes? | 6.507 | 6.917 | 8.333 | **6.705** |
| 11 | In any baby with seizures does levetiracetam improve need for second-line anti-convulsants when compared to phenobarbitone? | 6.649 | 6.643 | 6.333 | **6.637** |
| 12 | In term infants with a bilious vomit who are assessed by a senior neonatologist as being well; does transfer to a specialised unit for urgent upper gastrointestinal contrast improve survival; quality of life and adverse events compared to close clinical monitoring by the local neonatal team? | 6.640 | 6.688 | 6.250 | **6.632** |
| 13 | In babies above 34 weeks gestation on the postnatal ward; is a blood glucose threshold of 2.0mmol/L non-inferior to a blood glucose threshold of 2.6mmol/L with regards to adverse events? | 6.667 | 6.688 | 4.000 | **6.585** |
| 14 | In infants born extremely preterm (< 28 weeks) does 1 to 1 nursing care until 28 weeks corrected gestation improve survival and all core neonatal outcomes compared to standard nursing allocations based on intensive care support required? | 6.392 | 6.826 | 8.000 | **6.582** |
| 15 | In babies born preterm does a post-discharge home intervention package of brain stimulation exercises improve neurodevelopment when compared to standard care? | 6.216 | 7.500 | 8.000 | **6.551** |
| 16 | Does therapeutic hypothermia (cooling) improve brain injury and long term neurodevelopmental outcomes in preterm infants (> 30 weeks) who have suffered a hypoxic injury? | 6.237 | 7.474 | 7.600 | **6.540** |
| 17 | In infants with a prenatally diagnosed gastrointestinal anomaly does planned delivery in a unit with co-located neonatal surgical unit (no ambulance transfer required) improve survival; parental experience and adverse events? | 6.347 | 7.000 | 7.500 | **6.505** |
| 18 | In preterm babies does high dose caffeine (10-20mg/kg/day) improve survival; brain injury and cognition compared to low dose caffeine (5mg/kg/day)? | 6.316 | 6.667 | 7.800 | **6.455** |

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| 19 | In preterm infants does enhanced monitoring from birth to 72 hours of life (with near infrared spectroscopy (NIRS); transcutaneous CO2; spO2; heart rate and arterial BP) improve core neonatal outcomes compared to standard monitoring? | 6.395 | 6.471 | 7.333 | **6.434** |
| 20 | In extremely preterm infants that are ventilator dependent does early dexamethasone treatment (2 weeks of age) compared to late dexamethasone treatment (4 weeks of age) improve survival; bronchopulmonary dysplasia and cognition? | 6.360 | 6.588 | 7.250 | **6.438** |
| 21 | In extremely preterm infants (< 28 weeks) do elective caesarean sections or vaginal deliveries result in better survival; brain injury and cognition? | 6.203 | 6.773 | 8.400 | **6.436** |
| 22 | If a mother is in preterm labour and expected to deliver imminently does administering a second dose of antenatal steroid early improve survival and bronchopulmonary dysplasia compared to standard care (not administering a second dose until the standard time period)? | 6.289 | 6.765 | 7.200 | **6.418** |
| 23 | In extremely preterm infants < 28 weeks does routine high frequency oscillatory ventilation (HFOV) improve survival; cognition and bronchopulmonary dysplasia when compared to standard ventilation? | 6.316 | 6.588 | 7.250 | **6.402** |
| 24 | In extremely preterm babies does restrictive total fluid (60; 90; 120; 150ml/kg/day) lead to improved survival and bronchopulmonary dysplasia when compared to liberal total fluid (90; 120; 150; 180; 200ml/kg/day)? | 6.360 | 6.333 | 6.000 | **6.344** |
| 25 | In extremely preterm infants does maintaining a midline head position for the first 72 hours of life improve survival and brain injury when compared to standard care? | 6.014 | 7.400 | 6.750 | **6.327** |
| 26 | In preterm babies who develop hyperglycaemia (>12mmol/L) should we treat with an insulin infusion or reduce the glucose infusion rate; to maximise growth and long term metabolic outcomes? | 6.373 | 6.316 | 5.250 | **6.316** |
| 27 | In preterm infants with echocardiographically confirmed persistent pulmonary hypertension of the newborn (PPHN) does inhaled nitric oxide improve survival; bronchopulmonary dysplasia and brain injury compared to no treatment? | 6.211 | 6.688 | 7.000 | **6.316** |
| 28 | In extremely preterm infants does on-demand haemodynamic assessment guided choice of inotrope therapy improve survival and other core outcomes compared to standard unit protocols? | 6.387 | 6.000 | 5.667 | **6.311** |

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| 29 | In babies diagnosed with gastro-oesophageal reflux does the use of anti-reflux medications improve outcomes such as bronchopulmonary dysplasia; sepsis and quality of life when compared with non-pharmacological support? | 6.107 | 6.750 | 7.200 | **6.308** |
| 30 | In preterm babies showing feeding cues whilst on non-invasive respiratory support; does commencing oral feeding (compared to waiting) improve outcomes such as breastfeeding rates; oral aversion and reflux? | 6.027 | 7.080 | 6.500 | **6.302** |
| 31 | Does point of care ultrasound guided umbilical venous catheter (UVC) position adjustments reduce workload; X-ray exposure and adverse events compared to standard X-ray guided UVC position adjustments? | 6.280 | 6.385 | 6.000 | **6.289** |
| 32 | In preterm babies do high nutrient enteral/ parenteral nutrition strategies (macronutrients at upper end of recommended intakes) improve core neonatal outcomes when compared with lower nutrient enteral/ parenteral nutrition strategies (macronutrients at lower levels of recommended intakes) without adverse events? | 6.329 | 5.950 | 7.000 | **6.280** |
| 33 | Does increased staffing with dedicated allied health professionals or care support workers to support parents with caring for their baby improve quality of life; length of stay and parental wellbeing over standard staffing? | 5.622 | 7.875 | 8.000 | **6.279** |
| 34 | In preterm babies requiring parenteral nutrition; does early parenteral nutrition within 8 hours of birth improve survival and neurodevelopmental outcomes when compared to late parenteral nutrition after 48 hours of life? | 6.053 | 6.667 | 7.800 | **6.265** |
| 35 | In preterm infants does prophylactic hydrocortisone treatment from day 1 to 10 improve survival and other core neonatal outcomes compared to a placebo? | 6.184 | 6.188 | 6.500 | **6.198** |
| 36 | In ex-preterm babies with inguinal hernias; does repair prior to discharge improve adverse events such as incarceration; when compared with repair after discharge? | 6.187 | 6.267 | 6.000 | **6.191** |
| 37 | In extremely preterm infants should structured blood pressure management be aiming for a target of greater than 30mmHg or greater than gestational age; to improve survival and brain injury? | 6.080 | 6.563 | 6.333 | **6.170** |
| 38 | In preterm infants does starting treatment with early probiotics (<24 hours of birth) versus later probiotics (when tolerating trophic feeds) reduce risk of necrotising enterocolitis; sepsis; dysbiosis? | 5.960 | 6.739 | 6.333 | **6.154** |

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| 39 | Does being born on a facilitative unit that promotes family centered care improve neurodevelopmental outcomes; length of stay and readmissions compared with traditional neonatal care? | 5.575 | 7.480 | 7.600 | **6.136** |
| 40 | In preterm babies does an embedded feeding team (comprising SALT; feeding advisor and dietetics) improve growth; breast-feeding rates; readmissions and parent-infant bonding as compared with standard care? | 5.600 | 7.625 | 6.800 | **6.125** |
| 41 | In moderately preterm infants (32-27 weeks) does immediate kangaroo mother care/ skin-to-skin for a minimum period of time per day improve breast-feeding rates; hypoglycaemia and autism spectrum disorders compared with standard care? | 5.649 | 7.440 | 6.333 | **6.114** |
| 42 | In all infants with cardiovascular instability; does access to targeted functional echocardiography improve outcomes such as survival; brain injury and kidney injury compared to standard care? | 5.960 | 6.313 | 7.000 | **6.053** |
| 43 | In all babies requiring admission to NICU at birth; does a delivery room cuddle with the parents improve survival; parental mental health and breast milk production when compared with no delivery room cuddle? | 5.493 | 7.400 | 7.333 | **6.047** |
| 44 | In babies with oesophageal atresia does routine placement of a transanastomotic tube (TAT) improve strictures; need for dilatations and need for rescue feeding method; when compared with no TAT placement? | 5.899 | 6.615 | 6.333 | **6.023** |
| 45 | In term babies over 48 hours of life; is a blood glucose threshold of 2.6mmol/L non-inferior to a blood glucose threshold of 3.0mmol/L for adverse events; cognition and breastfeeding rates? | 5.947 | 6.438 | 4.000 | **5.968** |
| 46 | In term babies receiving therapeutic hypothermia (cooling) does early parenteral nutrition improve survival and cognition when compared to only commencing parenteral nutrition after one week if feeds cannot be established? | 5.671 | 6.591 | 7.500 | **5.941** |
| 47 | In infants < 32 weeks gestation with patent ductus arteriosus (PDA) does artificial closure (ligation or medical) improve survival and bronchopulmonary dysplasia compared with supportive management only? | 5.747 | 6.529 | 6.500 | **5.917** |
| 48 | In all babies admitted to NICU; does a routine clinical psychologist assessment and ongoing support with weekly parent groups improve long term neonatal outcomes and parental mental health; compared to no psychology interventions? | 5.486 | 7.040 | 5.667 | **5.867** |

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| 49 | In infants requiring higher level care does being delivered at a level three NICU improve survival; bronchopulmonary dysplasia and adverse events in comparison to postnatal transfer from a different unit? | 5.467 | 6.792 | 7.167 | **5.867** |
| 50 | In preterm infants; does adopting a 'golden hour' approach completing all procedures within one hour of birth improve survival; BPD and cognition when compared to standard care? | 5.413 | 7.235 | 7.800 | **5.856** |
| | **Round 2** | | | | |
| 51 | Does the support of a dedicated specialist lactation consultant on NICU from admission to discharge improve growth; breast-milk feeding and maternal mental health? | 5.751 | 6.676 | 6.889 | **6.080** |
| 52 | In extremely preterm infants who received a dose of surfactant at birth do repeated doses of surfactant at 48 and 72 hours improve survival and bronchopulmonary dysplasia when compared to standard care? | 5.812 | 6.500 | 7.813 | **6.078** |
| 53 | For all infants requiring neonatal care does a formal multi-disciplinary discharge pathway with nationally approval parental information and tailored education sessions reduce readmission; A&E attendances and improve parental wellbeing compared to standard local discharge pathways? | 5.467 | 7.100 | 7.294 | **6.075** |
| 54 | Does supplementation with breast milk fortifier after discharge or term age improve growth; breast-feeding rates and long term outcomes in preterm babies? | 5.909 | 6.418 | 6.111 | **6.054** |
| 55 | Does the use of loperamide post stoma formation improve parenteral nutrition related liver disease; line sepsis and length of stay when compared to placebo? | 5.968 | 6.000 | 7.500 | **6.049** |
| 56 | In babies diagnosed with necrotising enterocolitis does remote ischaemic condition improve survival; necrotising enterocolitis and duration of parenteral nutrition compared to standard care? | 5.808 | 6.600 | 7.091 | **6.043** |
| 57 | Does a psychology intervention supporting staff with regular reflective practice and psychoeducation improve staff sickness; staff retention and staff mental health issues compared to no psychological intervention for staff? | 5.570 | 7.014 | 6.118 | **6.042** |
| 58 | In preterm infants receiving less invasive surfactant administration does use of pharmacological methods alongside environmental measures improve success rates and comfort when compared to environmental measures alone (swaddling/ sucrose)? | 5.868 | 6.288 | 6.556 | **6.004** |

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| 59 | In preterm babies receiving donor milk due to insufficient mothers milk; is it superior to switch to preterm formula once on full feeds or wait until term corrected gestational age? | 5.885 | 6.254 | 6.125 | **5.996** |
| 60 | In preterm babies with chronic lung disease does extending caffeine therapy until term (rather than standard care of discontinuing around 34 weeks corrected gestation) improve survival and cognition? | 5.783 | 6.077 | 7.889 | **5.992** |
| 61 | In preterm babies requiring parenteral nutrition does higher range lipid (fats) intake or lower range lipid (fats) intake improve growth and long term metabolic outcomes? | 6.097 | 5.827 | 5.231 | **5.987** |
| 62 | In preterm infants does high dose vitamin D supplementation (>800 units) improve metabolic bone disease when compared to low dose vitamin D supplementation (< 400 units)? | 5.981 | 6.000 | 5.909 | **5.982** |
| 63 | In preterm babies whose mothers would like to establish exclusive breast-feeding; does exposure to routine bottle feeding reduce breast-feeding success compared to exposure to routine nasogastric feeding? | 5.661 | 6.565 | 6.611 | **5.969** |
| 64 | Does dopamine vs adrenaline use for hypotension in preterm infants result in improved survival; neurodevelopemental outcome at 24 months corrected age and reduced morbidity (such as necrotising enterocolitis and bronchopulmonary dysplasia) | 5.847 | 6.000 | 7.750 | **5.957** |
| 65 | Does follow up of moderate to late preterm infants to 5 years improve school age outcomes and health? | 5.486 | 6.800 | 7.000 | **5.953** |
| 66 | In neonates with meconium ileus and obstruction or post-laparotomy with obstruction; does saline or N-acetylcysteine treatment improve speed of establishing feeds or reduce the need for subsequent laparotomy when compared to supportive care? | 5.952 | 6.154 | 5.333 | **5.940** |
| 67 | In preterm infants with established chronic lung disease on invasive/non-invasive respiratory support at term corrected does a weaning course of prednisolone and azithromycin prophlyaxis improve home oxygen use and duration; readmissions with respiratory illnesses and length of stay? | 5.872 | 5.956 | 6.818 | **5.932** |
| 68 | Does the use of a respiratory function monitor to guide tidal volumes at birth reduce short-term need for ventilation and long-term outcomes of bronchopulmonary dysplasia; brain injury and 2 year outcomes? | 5.764 | 6.000 | 7.667 | **5.929** |

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| 69 | In extremely preterm infants < 28 weeks is assist control ventilation (with volume targeting) superior to SIMV (with volume targeting) with regards to survival; ventilation days and bronchopulmonary dysplasia? | 5.795 | 6.105 | 7.000 | **5.928** |
| 70 | In babies diagnosed with NEC does treatment with pentoxifylline improve survival; duration of PN and brain injury compared to standard care? | 5.795 | 6.105 | 7.091 | **5.928** |
| 71 | In preterm babies does targeting higher oxygen saturations of 92-97% lead to improved survival without complications such as NEC (when compared to standard care? | 5.647 | 6.113 | 8.111 | **5.918** |
| 72 | Does providing ongoing psychology support in the community as part of the routine discharge package improve quality of life; bonding and parental mental health compared to routine discharge with no psychology follow-up? | 5.204 | 7.042 | 7.316 | **5.914** |
| 73 | In term babies admitted to NICU for respiratory support would lowering the target saturations range to > 90% (rather than standard target) improve length of stay and duration of respiratory support without increasing adverse outcomes? | 5.769 | 5.980 | 7.235 | **5.911** |
| 74 | In extremely preterm infants with patent ductus arteriosus on a screening echocardiogram does early medical treatment (< 7 days) improve core neonatal outcomes compared with no treatment? | 5.755 | 6.205 | 6.538 | **5.891** |
| 75 | In preterm babies < 32 weeks with an oxygen requirement of over 40% does routine intubation and ventilation improve survival and bronchopulmonary dysplasia when compared to intubation based solely on clinical indications such as apnoea? | 5.639 | 6.255 | 7.353 | **5.877** |
| 76 | Does providing a bespoke psychological intervention to parents who witnessed a serious incident (either for their own or a different baby) improve parental trauma scores; parental mental health and quality of life compared to not providing bespoke support? | 5.187 | 6.931 | 7.316 | **5.876** |
| 77 | Does education for health professionals about the support needs of ethnically diverse families reduce increased neonatal mortality risk; when compared to standard staff training? | 5.229 | 6.839 | 7.750 | **5.872** |
| 78 | Does a weekly ‘allied health professional’ ward round with parents present improve parental satisfaction; when compared to allied health professional ward rounds without parental presence? | 5.200 | 6.904 | 7.500 | **5.861** |

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| 79 | In babies with seizures does maintenance topiramate improve seizure control and brain injury when compared to phenobarbitone? | 5.716 | 6.306 | 6.273 | **5.851** |
| 80 | In extremely preterm infants with respiratory distress requiring surfactant administration is elective intubation and ventilation preferable to less-invasive-surfactant-administration to improve pneumothorax rates and bronchopulmonary dysplasia? | 5.696 | 6.395 | 5.933 | **5.837** |
| 81 | In babies on the NICU; do parent-led ward rounds improve quality of life; parental mental health and breast-feeding rates in comparison to standard clinician led ward rounds? | 5.207 | 6.819 | 7.053 | **5.834** |
| 82 | In babies with respiratory distress syndrome should a second dose of surfactant be given at 30% or 40% to improve bronchopulmonary dysplasia rates and other core neonatal outcomes? | 5.740 | 5.750 | 7.400 | **5.827** |
| 83 | Do preterm infants have lower scores on standardised Speech and Language scales at 18 months; 3 years and 5 years compared to term born infants demonstrating the need for fully funded; robust speech and language services at neonatal discharge? | 5.331 | 6.403 | 7.625 | **5.808** |
| 84 | In extremely preterm infants that are ventilator dependent on day 8 of life does a treatment course of nebulised budesonide as compared to placebo improve survival; bronchopulmonary dysplasia; and length of stay? | 5.614 | 6.071 | 7.600 | **5.798** |
| 85 | In babies born pre-term; who have bronchopulmonary dysplasia; does a standardised ventilation weaning plan improve duration of ventilation; length of hospital stay; growth; quality of life and neurodevelopmental outcomes at 12 and 24 months? | 5.597 | 6.150 | 7.200 | **5.794** |
| 86 | In babies with suspected hypoxic ischaemic encephalopathy in level 2 neonatal units; does the use of telemedicine to aid diagnosis improve long-term neurodevelopmental outcomes? | 5.366 | 6.565 | 7.333 | **5.760** |
| 87 | In very preterm infants at delivery does setting initial FiO2 at 0.6 versus 0.3 and targeting oxygen saturations of 80-85% at 5 mins and 85-95% at 10 mins or later increase survival without disability? | 5.577 | 5.941 | 8.000 | **5.725** |
| 88 | For parents of preterm infants does delivering detailed information of future health risks at discharge; improve quality of life; parental satisfaction and | 5.099 | 6.300 | 7.375 | **5.596** |

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| | parental mental health; when compared to providing it at a later timepoint (for example 12 months corrected age)? | | | | |
| 89 | In babies diagnosed antenatally with congenital diaphragmatic hernia; does the use of intranasal sedation for intubation at delivery; compared to no sedation lead to fewer intubation attempts; better cardiorespiratory stability and improved long term neurodevelopmental outcomes? | 5.423 | 6.286 | 6.250 | **5.596** |
| 90 | In preterm infants born at <28w gestation does regular screening for Ureaplasma colonisation and treatment where indicated; improve outcomes (bronchopulmonary dysplasia; length of stay)? | 5.580 | 5.300 | 5.250 | **5.530** |
| 91 | Does a structured package of malnutrition investigations improve outcomes such as nutritional deficiences; growth and core long-term outcomes? | 5.211 | 5.792 | 7.500 | **5.525** |
| 92 | In all babies requiring intubation; does the nasal route offer an acceptable alternative that results in fewer unplanned extubations? | 5.356 | 5.500 | 6.667 | **5.465** |
| 93 | In all infants (including preterm infants) with suspected hypoxic ischaemic encephalopathy; does intervention with therapeutic hypothermia (cooling) affect visual development; when compared to standard care? | 4.814 | 6.409 | 7.667 | **5.347** |
| 94 | Does a smoking cessation support package delivered in NICU by NICU staff reduce parental smoking relapse rates by 12 months post discharge? | 4.986 | 5.500 | 6.000 | **5.192** |

**Lower Prioritised Questions**

| **Rank** | **Question** | **Doctors/ Researchers** | **Nurses/ AHPs** | **Parents/ Former Patients** | **Mean Score** |
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| 95 | Does regular ultrasound monitoring of umbilical lines to identify associated thrombus improve core neonatal outcomes? | 4.861 | 5.000 | 5.200 | **4.905** |
| 96 | Do breastfeeding preterm infants who receive routine daily vitamin K supplementation post-discharge have lower prevalence of vitamin K deficiency in infancy? | 4.319 | 5.038 | 5.714 | **4.590** |

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| 97 | For all babies requiring neonatal care; does a formal nursing training package on length measurement improve reliability and validity of measurements when compared to standard care? | 3.771 | 5.267 | 5.800 | **4.295** |
| | **Round 1** | | | | |
| 98 | Does referral to early intervention occupational therapy at the point of neonatal discharge improve cognition; quality of life and social-emotional outcomes at school age; compared to no routine occupational therapy referral? | 5.539 | 6.500 | 7.222 | **5.968** |
| 99 | In babies undergoing therapeutic hypothermia does midazolam sedation rather than standard care with morphine sedation improve brain injury and cognition? | 5.723 | 6.556 | 6.500 | **5.968** |
| 100 | Does dedicated physiotherapy support after discharge improve parental and infant mental health; compared to no physiotherapy support? | 5.544 | 6.556 | 6.500 | **5.966** |
| 101 | In extremely preterm infants that are ventilator dependent on day 8 of life and likely to need pressure support ventilation at 36 weeks corrected gestation does a treatment course of hydrocortisone; as compared to a treatment course of dexamethasone improve survival and bronchopulmonary dysplasia? | 5.832 | 6.083 | 6.778 | **5.940** |
| 102 | In babies diagnosed with necrotising enterocolitis does therapeutic hypothermia improve survival and brain injury when compared to standard care? | 5.667 | 6.733 | 7.000 | **5.939** |
| 103 | In extremely preterm infants does limiting routine physical examination to times of clinical/parental or nursing concerns improve survival and complications of prematurity when compared to daily routine examination on ward rounds? | 5.583 | 6.767 | 6.571 | **5.934** |
| 104 | In preterm infants with respiratory distress syndrome requiring surfactant therapy is the best mode of delivery an iGel or a less-invasive-surfactant-administration catheter to improve success rates and mechanical ventilation rates? | 5.879 | 6.083 | 5.900 | **5.917** |
| 105 | In preterm babies receiving nasogastric feeds; does routinely aspirating compared to not routinely aspirating improve time to full enteral feeds; growth and length of stay without adverse events? | 6.104 | 5.417 | 5.600 | **5.894** |

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| 106 | When accessing lines does a sterile aseptic technique improve survival and sepsis over an aseptic non-touch technique? | 5.819 | 5.818 | 6.750 | **5.885** |
| 107 | Does a staff and parental training package on psychologically informed environments; trauma-informed care and compassion focused approaches improve core neonatal outcomes and parental mental health? | 5.077 | 7.077 | 7.364 | **5.883** |
| 108 | In infants with chronic lung disease does diuretic therapy improve home oxygen rates and neurodevelopmental outcomes when compared to no diuretics? | 5.653 | 6.077 | 7.500 | **5.869** |
| 109 | In preterm babies requiring parenteral nutrition does higher range energy (calorie) intake or lower range energy (calorie) intake improve growth and long term metabolic outcomes? | 5.854 | 5.867 | 6.000 | **5.865** |
| 110 | In all babies admitted to NICU; does a dedicated education training package covering unit familiarisation & protocols; parenting issues; financial support and bonding improve parental mental health alongside long-term neonatal outcomes; when compared to standard care? | 5.434 | 6.410 | 6.818 | **5.857** |
| 111 | In preterm babies does targeting tight control of weight gain along birth centile using calorific interventions improve outcomes when compared to allowing growth trajectory below birth centile (as per standard growth using population data)? | 6.031 | 5.500 | 5.375 | **5.852** |
| 112 | In all infants characterised as having circulatory failure; does the use of certain biomarkers improve survival and brain injury when compared to standard monitoring using blood pressure? | 5.663 | 6.381 | 6.429 | **5.847** |
| 113 | Does access to specialist neonatal respiratory physiotherapy (percussion/ treatment techniques) compared to neonatal staff training on physiotherapy techniques improve adverse events and neonatal outcomes? | 5.440 | 6.381 | 6.429 | **5.824** |
| 114 | In invasively ventilated extremely preterm infants is extubation to synchronised non-invasive positive pressure ventilation (NIPPV) or non-synchronised NIPPV superior when considering extubation success; survival and bronchopulmonary dysplasia? | 5.535 | 6.423 | 7.222 | **5.816** |
| 115 | Does targeted screening and needs assessment of social determinants (housing; safety; mental health; parental health literacy; transport needs; | 5.597 | 6.237 | 5.556 | **5.790** |

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| | food security; community support) improve survival; quality of life and adverse events? | | | | |
| 116 | In extremely preterm babies < 28 weeks is the use of neurally adjusted ventilatory assist (NAVA) ventilation with extubation to non-invasive NAVA (NIV NAVA) superior to conventional ventilation with extubation to NIPPV/ CPAP with regards to extubation success and bronchopulmonary dysplasia? | 5.593 | 6.333 | 6.333 | **5.770** |
| 117 | In preterm babies does sling provision and education to facilitate skin-to-skin contact improve parental wellbeing and weight gain when compared to standard care? | 5.276 | 6.590 | 6.200 | **5.760** |
| 118 | In extremely preterm infants with established chronic lung disease at 36 weeks corrected age; does sildenafil treatment improve survival compared with a placebo? | 5.748 | 5.696 | 6.000 | **5.756** |
| 119 | In preterm babies requiring parenteral nutrition does high amino acid intake improve growth and long term metabolic outcomes compared to standard intake? | 5.807 | 5.724 | 5.143 | **5.750** |
| 120 | Does implementation of formal parent peer support with meetings; social media and one-to-one peer support improve length of stay; readmissions and parental mental health compared to informal parental peer support? | 5.289 | 6.500 | 6.300 | **5.742** |
| 121 | In ex-preterm babies discharged home; does a community based sensory processing workshop improve infant regulation; improve bonding and decrease autism spectrum disorders compared to routine care? | 5.342 | 6.378 | 6.444 | **5.738** |
| 122 | For subsequent pregnancies after a neonatal admission; would a dedicated antenatal counselling and support programme improved parental anxiety and neonatal outcomes compared to no support programme? | 5.163 | 6.447 | 7.600 | **5.734** |
| 123 | In all infants receiving invasive or non-invasive respiratory support does prone or supine positioning improve the number of ventilation days and duration of supplemental oxygen? | 5.327 | 6.067 | 8.000 | **5.690** |
| 124 | Does an occupational therapist led parental training session and ongoing support regarding reading infant cues and participation in caregiving improve bonding and parental confidence compared to standard parental support? | 5.039 | 6.667 | 6.778 | **5.672** |

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| 125 | In preterm infants at risk of necrotising enterocolitis does treatment with gut-derived IFN-y-releasing CD4+ T cells improve survival; brain injury and quality of life when compared to current practice? | 5.403 | 6.875 | 6.833 | **5.671** |
| 126 | In babies requiring long term parenteral nutrition (PN); does supporting an earlier discharge home (when stable PN established) compared to standard care improve quality of life for families without increased risk? | 5.333 | 6.147 | 7.125 | **5.667** |
| 127 | In term infants with congenital diaphragmatic hernia is extracorporeal membrane oxygenation (ECMO) or high-frequency oscillatory ventilation (HFOV) superior to improve survival; brain injury and quality of life? | 5.358 | 6.360 | 7.125 | **5.664** |
| 128 | In preterm babies requiring parenteral nutrition does high vitamin D intake improve growth and long-term metabolic outcomes compared to standard intake? | 5.678 | 5.655 | 5.375 | **5.653** |
| 129 | In formula fed babies born moderately preterm at 34 to 37 weeks gestation does enhanced nutrition support improve growth and long term cognition; when compared to term formula? | 5.547 | 5.821 | 6.000 | **5.650** |
| 130 | Do regular occupational therapy interventions for all babies admitted to NICU improve cognition; adverse events and decrease sensory processing disorders in comparison to minimal (<1 day per week) occupational therapy input? | 5.218 | 6.275 | 6.556 | **5.646** |
| 131 | In all babies does next generation whole genome sequencing improve the diagnostic/prognostic yield compared to current newborn screening practices without adverse ethical issues? | 5.622 | 5.333 | 6.625 | **5.640** |
| 132 | Does an occupational therapist led staff training session about sensitive neonatal handling improve long term outcomes such as sensory processing disorders and improve staff-parent relationships; compared to standard staff training? | 5.053 | 6.590 | 6.200 | **5.629** |
| 133 | Does circadian rhythm entrainment with nocturnal melatonin improve survival and neurodevelopmental impairment in infants at high risk for neurological injury (preterm < 28 weeks with peri-ventricular leukomalacia/ grade 3/4 intra-ventricular haemorrhage or term babies with hypoxic ischaemic encephalopathy) when compared to placebo? | 5.506 | 5.739 | 6.571 | **5.624** |

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| 134 | In ex-preterm infants is early or late weaning on solids preferable with regards to growth; feeding behaviours and allergy? | 5.284 | 6.079 | 6.500 | **5.580** |
| 135 | In all babies requiring pre-medications for intubation is propofol or fentanyl / suxamethonium superior in improving survival and bronchopulmonary dysplasia? | 5.412 | 5.720 | 6.900 | **5.577** |
| 136 | In extremely preterm babies in the delivery room; does oxygen targeting based on near infrared spectroscopy (NIRS) (rather than SpO2) lead to improved survival and other core neonatal outcomes? | 5.265 | 6.320 | 7.167 | **5.558** |
| 137 | For parents of preterm infants does detailed information about future health risks (stroke; high blood pressure and heart disease) improve quality of life; parental satisfaction and parental mental health compared to no information? | 5.193 | 6.115 | 7.714 | **5.552** |
| 138 | Does provision of regular neonatal occupational therapy improve parental and staff perceptions of the developmental benefits for high-risk infants; compared to minimal occupational therapy input? | 5.013 | 6.325 | 6.500 | **5.543** |
| 139 | In preterm babies requiring parenteral nutrition do lower energy:protein ratios improve growth and long term metabolic outcomes compared to standard ratios? | 5.570 | 5.552 | 5.143 | **5.541** |
| 140 | In babies born as part of multiple births what is the effect of separation at any part of the neonatal journey on cognition; quality of life and adverse events? | 4.671 | 6.718 | 7.778 | **5.540** |
| 141 | When considering stopping antibiotics on the NNU; does the use of procalcitonin reduce the duration of antibiotics courses without adverse events compared to standard management using C-reactive protein? | 5.647 | 5.067 | 5.250 | **5.537** |
| 142 | In all babies being treated for sepsis do continuous vancomycin infusions increase survival and sepsis when compared to traditional multiple daily dose regimens? | 5.463 | 5.400 | 6.667 | **5.525** |
| 143 | Is plasmalyte or sodium chloride a better choice of bolus fluid for preterm infants with presumed hypovolaemia or poor perfusion? | 5.412 | 6.200 | 5.400 | **5.524** |
| 144 | Does a necrotising enterocolitis scoring tool incorporating parental views improve survival; sepsis and necrotising enterocolitis compared to necrotising enterocolitis scoring tools incorporating only professional views? | 5.092 | 6.682 | 6.375 | **5.519** |

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| 145 | In preterm infants does the use of freshly expressed maternal milk a couple of times a day (as opposed to standard care with frozen or refrigerated maternal milk) improve growth and long term neonatal outcomes? | 5.351 | 5.561 | 6.600 | **5.497** |
| 146 | In all preterm babies < 32 weeks does nasal intubation rather than oral intubation improve feeding problems at 3 months corrected age? | 5.010 | 6.545 | 6.800 | **5.479** |
| 147 | Does parental presence during handovers improve parental satisfaction without increasing handover duration; compared to parents being asked to step outside? | 4.831 | 6.282 | 7.300 | **5.476** |
| 148 | In infants requiring sedation during ventilation does dexmedetomidine improve cognition and quality of life compared to standard care with an opiate infusion? | 5.263 | 6.000 | 6.143 | **5.471** |
| 149 | In babies on the postnatal ward receiving IV antibiotics for risk factors with a raised C-reactive protein; does performing a lumbar puncture (compared to not performing a lumbar puncture) lead to prolonged duration of stay or any adverse events? | 5.274 | 5.875 | 6.429 | **5.470** |
| 150 | In babies transferred between different NICUs does a psychologist supported 'repatriation' training package for parents improve parental mental health? | 4.909 | 6.436 | 6.000 | **5.468** |
| 151 | In preterm babies requiring parenteral nutrition does high vitamin A intake improve growth and long-term metabolic outcomes compared to standard intake? | 5.437 | 5.621 | 5.250 | **5.468** |
| 152 | Does giving an extra dose of caffeine prior to planned extubation or within 2 hours of unplanned extubation increase extubation success (remaining extubated at 5 days) compared to standard caffeine therapy? | 5.163 | 5.889 | 6.833 | **5.441** |
| 153 | In extremely preterm infants does 30 minutes of daily conversation with a parent or caregiver improve cognition and quality of life compared with no dedicated conversation? | 4.865 | 6.154 | 6.778 | **5.418** |
| 154 | In infants at risk of hypoglycaemia on the postnatal ward; does the use of donor milk for feed supplementation (as opposed to standard care with formula or glucose gel) improve maternal breast-feeding rates; hypoglycaemia episodes and quality of life? | 5.053 | 5.821 | 7.333 | **5.406** |

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| 155 | Do tongue-tie interventions (laser or ligation) improve time taken to establish breast feeding; duration of breast feeding and parental satisfaction? | 5.242 | 5.605 | 6.100 | **5.399** |
| 156 | In preterm infants do routine clotting screens on admission (with corrections of derangements) lead to improve survival; brain injury and cognition compared to not performing a clotting screen unless clinically indicated? | 5.361 | 5.176 | 6.286 | **5.393** |
| 157 | In preterm babies does enteral insulin administration improve survival; sepsis and necrotising enterocolitis when compared to a masked placebo medication? | 5.494 | 4.769 | 6.125 | **5.380** |
| 158 | In babies with direct antiglobulin test (DAT) positive jaundice on the postnatal ward; does routine folic acid supplementation improve cognition; quality of life and adverse events? | 5.262 | 5.600 | 5.875 | **5.366** |
| 159 | In 28 to 32 week infants on non-invasive respiratory support is the best method to determine the need for surfactant administration lung ultrasound scoring or clinical signs/X-ray? | 5.257 | 5.560 | 5.900 | **5.360** |
| 160 | In preterm babies requiring parenteral nutrition does high folic acid intake improved growth and long-term metabolic outcomes compared to standard intake? | 5.291 | 5.552 | 5.250 | **5.350** |
| 161 | Would implementation of a 'buddy system' during the immediate postnatal period between neonatal and maternity staff looking after admitted babies and admitted mothers help to ensure parental presence at key neonatal aspects alongside managing maternal health; thus preventing early discharge and improving breast-milk production? | 4.842 | 6.105 | 6.111 | **5.325** |
| 162 | In preterm infants with suspected necrotising enterocolitis undergoing laparotomy does tranexamic acid improve survival and adverse events compared to no tranexamic acid treatment? | 5.118 | 5.750 | 6.333 | **5.296** |
| 163 | In preterm infants; does delivery and management in a 'newborn individualized developmental care and assessment programme (NIDCAP) certified unit improve cognition; length of stay and breast-feeding rates when compared to management in a non-NIDCAP certified unit? | 4.592 | 6.867 | 5.833 | **5.268** |
| 164 | Does zinc supplementation of preterm infants improve growth? | 5.266 | 5.032 | 5,889 | **5.254** |

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| 165 | In infants undergoing surgery does routine cerebral near infrared spectroscopy (NIRS) monitoring to target optimal analgesia improve cognition when compared to routine care? | 5.125 | 5.500 | 5.857 | **5.243** |
| 166 | In infants post-surgery does oxycodone analgesia reduce length of ventilation and length of hospital stay when compared to standard care with an opiate infusion? | 5.039 | 5.762 | 6.000 | **5.243** |
| 167 | How can 'memory-milk-gift-initiatives' best be implemented to support bereaved mothers with donating breast milk; and do these initiatives improve parental experiences and maternal mental health? | 4.852 | 5.675 | 6.900 | **5.239** |
| 168 | In infants who have been successfully intubated is ultrasound or X-ray the best method to confirm endotracheal tube tip position and avoid adverse events? | 5.118 | 5.240 | 6.100 | **5.212** |
| 169 | In babies diagnosed with brain injury; does specialist neonatal music therapy improve cognition; quality of life and short term physiological parameters when compared with standard neonatal care? | 4.766 | 5.838 | 6.300 | **5.210** |
| 170 | In preterm infants on the neonatal unit requiring respiratory support (invasive or non-invasive) does respiratory syncytial virus (RSV) prophylaxis improve survival and bronchopulmonary dysplasia compared to standard care (no RSV prophylaxis whilst an inpatient)? | 4.842 | 5.480 | 7.778 | **5.156** |
| 171 | Does a dedicated sibling support pack improve neonatal outcomes and family bonding; compared to no sibling support pack? | 4.481 | 6.237 | 5.818 | **5.127** |
| 172 | Do individualised infant diaries improve parental mental health and family bonding compared to no infant diary? | 4.675 | 5.872 | 5.667 | **5.120** |
| 173 | In clinically well term babies with > 10% weight loss does performing serum electrolyte measurements decrease survival; sepsis and seizures when compared to not measuring electrolytes? | 4.893 | 5.720 | 5.571 | **5.112** |
| 174 | In clinically well babies noted to have a raised cord lactate (but no TOBY criteria met) does observation and detailed clinical assessment lead to reduced length of stay and increased breast-feeding rates when compared to sequential blood gases with possible admission for intravenous fluids? | 5.024 | 5.474 | 5.000 | **5.103** |

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| 175 | In intubated preterm infants does a short course of diuretics prior to extubation improve bronchopulmonary dysplasia and cognition when compared to a placebo? | 4.901 | 5.400 | 5.778 | **5.052** |
| 176 | In term babies establishing breast-feeding on the post-natal ward; does the use of cup; syringe or spoon feeding increase the aspiration risk over bottles? | 4.872 | 5.308 | 5.700 | **5.049** |
| 177 | In infants born to mothers with a history of maternal thyrotoxicosis; does inpatient observations for 48 hours with follow-up thyroid blood tests on day 5 lead to improved survival; cognition and adverse events when compared to routine postnatal care with detailed safety net advice? | 5.123 | 4.941 | 4.333 | **5.048** |
| 178 | In preterm babies with hyperbilirubinaemia; does using specific phototherapy radiance improve survival; brain injury and cognition when compared to using maximal phototherapy treatment? | 4.707 | 5.900 | 6.143 | **5.018** |
| 179 | In babies receiving end of life care; does specialist neonatal music therapy improve quality of life; parental experience and bereavement support in comparison to standard end of life care? | 4.526 | 5.784 | 5.700 | **5.000** |
| 180 | In neonates requiring surgery does deferring surgery until bilirubin is below a certain clinical level improve wound healing; length of stay and readmission rates? | 4.743 | 5.784 | 5.700 | **4.989** |
| 181 | In unwell term infants admitted to the NICU; does the routine addition of anti-viral treatments improve survival and quality of life compared to standard treatment with antibiotics only? | 4.524 | 5.368 | 7.100 | **4.894** |
| 182 | In preterm babies does use of a fluidised positioning pillow from birth improve incidence of scaphocephaly or plagiocephaly at discharge? | 4.378 | 6.200 | 5.333 | **4.890** |
| 183 | In preterm infants with patent ductus arteriosus does treatment with indomethacin improve survival when compared to placebo treatment? | 4.682 | 5.647 | 5.167 | **4.861** |
| 184 | In neonates post-surgery does giving prophylactic antibiotics only if there is a left shift on the differential white blood cell count improve survival; sepsis and adverse events compared with no antibiotics? | 4.354 | 5.188 | 5.500 | **4.554** |
| 185 | Does routinely sending the endotracheal tube tip for microscopy, culture and sensitivity after extubation increase survival and sepsis? | 3.904 | 4.500 | 5.857 | **4.130** |

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| 186 | In preterm babies does taking a bath on the neonatal unit prior to discharge increase the risk of respiratory infections or other adverse events; when compared with no bath? | 3.623 | 4.568 | 4.778 | **3.992** |