








Early mobilisation and rehabilitation in the PICU: a UK survey

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ABSTRACT

Objective To understand the context and professional perspectives of delivering early rehabilitation and mobilisation (ERM) within UK paediatric intensive care units (PICUs).

Design A web-based survey administered from May 2019 to August 2019.

Setting UK PICUs.

Participants A total of 124 staff from 26 PICUs participated, including 22 (18%) doctors, 34 (27%) nurses, 28 (23%) physiotherapists, 19 (15%) occupational therapists and 21 (17%) were other professionals.

Results Key components of participants' definitions of ERM included tailored, multidisciplinary rehabilitation packages focused on promoting recovery. Multidisciplinary involvement in initiating ERM was commonly reported. Over half of respondents favoured delivering ERM after achieving physiological stability (n=69, 56%). All age groups were considered for ERM by relevant health professionals. However, responses differed concerning the timing of initiation. Interventions considered for ERM were more likely to be delivered to patients when PICU length of stay exceeded 28 days and among patients with acquired brain injury or severe developmental delay. The most commonly identified barriers were physiological instability (81%), limited staffing (79%), sedation requirement (73%), insufficient resources and equipment (69%), lack of recognition of patient readiness (67%), patient suitability (63%), inadequate training (61%) and inadequate funding (60%). Respondents ranked reduction in PICU length of stay (74%) and improvement in psychological outcomes (73%) as the most important benefits of ERM.

Conclusion ERM is gaining familiarity and endorsement in UK PICUs, but significant barriers to implementation due to limited resources and variation in content and delivery of ERM persist. A standardised protocol that sets out defined ERM interventions, along with implementation support to tackle modifiable barriers, is required to ensure the delivery of high-quality ERM.

INTRODUCTION

In the UK, approximately 20 000 children are admitted to paediatric intensive care units (PICUs) yearly,¹ and although most recover,

What is known about the subject?

- ⇒ Early rehabilitation and mobilisation (ERM) interventions are safe, feasible and effective within adult intensive care, but the evidence base in a paediatric setting is limited.
- ⇒ In critically ill adults, ERM delivery is tailored according to the patient's cardiovascular support requirements, levels of consciousness and tolerance levels.
- ⇒ Barriers to implementing ERM in paediatric intensive care units have been described in North America, but little is known about these within the UK NHS setting.

What this study adds?

- ⇒ Despite positivity toward the concept of early rehabilitation and mobilisation (ERM), less than 20% of UK paediatric intensive care units (PICUs) currently have an established ERM protocol to define ERM content and practice.
- ⇒ ERM initiation and delivery is collaborative, but there is wide variability on which patients can receive ERM and when this should be initiated.
- ⇒ The provision of a standardised protocol that sets out safe and defined ERM activities along with implementation support would tackle modifiable barriers of intervention delivery.
- ⇒ The most important barriers to ERM delivery in PICUs within the NHS are financial resources and staffing, lack of protocols for patient selection and ERM guidelines.

some develop longer-term physical, psychological and cognitive impairment.² These significant morbidities have been termed post-intensive care syndrome in paediatrics.³ Early rehabilitation and mobilisation (ERM) encompasses patient-tailored interventions, delivered within 7 days of admission, individually⁴ or in a bundled package⁵ to patients within intensive care settings. It is provided by health professionals from multiple disciplines



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and care-givers and may promote physical (eg, functional activities)⁴ and non-physical (eg, psychological and cognitive)⁶ recovery.

Within adult ICUs, ERM has been demonstrated to be safe, feasible and cost effective.^{7,8} It can shorten the length of ventilation, shorten the duration of intensive care and hospital stay with economic benefit, improve long-term physical functioning and return to independence and is recommended by National Institute for Health and Care Excellence.⁸ While ERM has been reported to be safe and feasible in PICUs,^{9–11} the patient population is different, and ERM is less well defined, leading to variability in practice. This variation in practice and components of interventions delivered has also been described in European PICUs.¹² At present, no national standardised care pathway for ERM exists within UK PICUs.

This study forms part of the National Institute for Health Research (NIHR) funded PERMIT study (NIHR HTA: 17/21/06) investigating ERM in children. This work was set out to understand reported practices and perceptions of ERM within the UK PICU context.

Our objectives were to:

- ▶ Explore how healthcare professionals describe and administer ERM using a qualitative approach.
- ▶ Identify and describe current ERM practice using a quantitative approach.
- ▶ Understand and quantify perceived barriers and facilitators of ERM, presenting findings using descriptive analysis.

METHODS

A web-based survey (administered through www.smart-survey.co.uk) was developed that included 25 questions (online supplemental material 1). A patient representative was involved in the design and development of the survey. A pilot survey was conducted among multidisciplinary health professionals (n=40) teams within two PICUs to assess acceptability and comprehensiveness. There were very few missing responses; therefore, no questions were removed, but five questions were rephrased to add clarity. Pilot responses were excluded from the main survey analysis.

A UK Paediatric Intensive Care Society Study-Group (PICS-SG) member of each UK PICU (n=29) was contacted via email and requested to identify and cascade to members of their local multidisciplinary team (including at least one physiotherapist, doctor and nurse) to complete the survey. Participating PICUs were sent a survey link to distribute between May 2019 and August 2019. Three follow-up reminders were sent at weekly intervals to non-responders.

Likert scales with the following categories (and associated scores)—always (5), very often (4), sometimes (3), seldom (2) and never (1)—were used to express the frequency of practice or level of agreement (using median and IQR of score). The ranking of perceived ERM benefits was calculated using the sum of ranked scores of respondents' top five important benefits (5

points for 1st place, reducing to 1 point for 5th place). Statistical analysis was performed using R V.x64 3.5.1 (R Foundation for Statistical Computing, Vienna, Austria).

Open-ended responses were analysed using a qualitative content analysis approach.¹³ Two researchers independently familiarised themselves with the data and conducted open coding, using NVIVO software for data management. Codes were then discussed, summarised and organised.^{14,15} In relevant sections of the paper, free-text quotes from respondents are reported to add context and clarity.¹⁶

Patient and public involvement

The pilot survey received input from multidisciplinary health professionals who were members of the UK PICS-SG. We also recruited a patient representative as part of the study team to ensure that the perspectives, experiences and preferences of children admitted to PICU were incorporated into the design and development of the survey. The patient representative was a parent of a child who had been admitted to PICU. They both contributed to the nature of questions considered in the survey to ensure the study outcome would be relevant to parents and members of the PICS-SG on dissemination.

RESULTS

Demographics

We received responses from PICS-SG link members in 26/29 (90%) UK PICUs. A total of 191 healthcare professionals opened the survey link, with 124 (65%) submitting responses.

Table 1 Characteristics of survey respondents (n=124 respondents)

Professional group	n (%)*
Nurse	34 (27)
Physiotherapist	28 (23)
Medical doctor (consultant)	22 (18)
Occupational therapist	19 (15)
Play therapist	7 (6)
Psychologist	7 (6)
Dietician	6 (5)
Speech and language therapist	1 (1)
Years of experience	n (%)*
<1 year	7 (6)
1 year to <5 years	27 (22)
5 years to <10 years	30 (24)
10 years to <15 years	14 (11)
15 years to <20 years	33 (27)
More than 20 years	15 (12)
*Percentages may not total 100 due to rounding.	

Table 2 Current views of ERM in PICU (n=121 respondents)

Current view of ERM in PICU	n (%)*
Crucial, should be the top priority in the care of PICU patients	15 (12)
Very important, should be a priority in the care of PICU patients	67 (55)
Important, should be a priority in the care of PICU patients	35 (29)
Somewhat important, should be considered in the care of PICU patients	4 (3)
Not of great importance, clinicians should bear it in mind in the care of PICU patients	0 (0)
Of minimal importance to the care of PICU patients	0 (0)
Of no importance to the care of the PICU patients	0 (0)

*Percentages may not total 100 due to rounding.
ERM, early rehabilitation and mobilisation; PICU, paediatric intensive care unit.

As shown in [table 1](#), the majority of respondents were nurses (n=34, 27%), physiotherapists (n=28, 23%) and doctors (n=22, 18%). There were also responses from occupational therapists (n=19, 15%), play therapists (n=7, 6%), psychologists (n=7, 6%), dieticians (n=6, 5%) and speech and language therapists (n=1, 1%). Almost three-quarters of health professionals had ≥5-year experience, with 48 (39%) having ≥15-year experience. The majority of respondents considered ERM to be a priority, either crucial (15, 12%), very important (67, 55%) or important (35, 29%) in the care of PICU patients ([table 2](#)).

Description of ERM

We invited respondents to describe ERM on their terms. Descriptions were provided by 104 (84%), which were summarised into four categories, ‘activity focused’, ‘tailored’, ‘promote recovery’ and ‘timing of ERM’ (see online supplemental file 2 and [table 1](#)). Overall, ERM was considered to be an individualised package of graded interventions based on an activity-focused programme, to reduce the sequelae of critical illness or injury. However,

responses differed for when ERM should be initiated, often emphasising the need for individualisation.

Availability of established ERM protocols

Respondents were asked to describe the content of established ERM protocols within their PICU. Only 12 participants (10%) reported working in a PICU with an established ERM protocol (n=5/26, 19% of PICUs). The most common components of ERM protocols were ‘physical therapy not requiring additional equipment’ (n=9/12, 75%) and ‘occupational therapy interventions’ (n=8/12, 67%). Only 4/12 (33%) referred to play therapy or speech and language therapy, and no ERM protocol specified input from psychologists or psychiatrists. All participants were asked about the content of non-ERM protocols in their PICU. Only 18/124 (15%) reported that guidance for physical or occupational therapy activities existed in other non-ERM protocols within PICU ([table 3](#)).

Recipients of ERM

Fifty-one (41%) respondents reported that all PICU patients ‘always’ or ‘very often’ received ERM (online supplemental file 2 and [table 2](#)). Overall, 14 (11%) respondents reported ‘seldom’ or ‘never’ delivering ERM.

ERM was reported to be more likely to be delivered to patients when PICU length of stay exceeded 28 days. Patients admitted for 28 days or more were more likely (n=91, 75%) to ‘always’ or ‘very often’ receive ERM compared with those admitted for shorter periods. Only 17 (13%) of those staying for less than 3 days, 44 (36%) of those admitted between three to 7 days and 73 (59%) of those admitted between seven to 28 days were more likely to receive ERM. Participants reported that patients with acquired brain injury (n=75, 60%) and severe developmental delay (n=54, 44%) were ‘always’ or ‘very often’ likely to receive ERM.

Perceived benefits of ERM

Participants ranked the 5 most important potential benefits of ERM out of 13 options ([figure 1](#) and [table 4](#)). The most important outcomes identified were (1) reduced PICU length of stay, (2) improved psychological outcomes

Table 3 Content of ERM and non-ERM protocols

Items	Within an ERM protocol (n=12 respondents) Yes n (%)	Within a non-ERM protocols (n=124 respondents) Yes n (%)
Physical therapy requiring additional equipment	9 (75)	18 (15)
Occupational therapy interventions	9 (75)	18 (15)
Physical therapy not requiring additional equipment	8 (67)	17 (14)
Speech and language therapy interventions	4 (33)	12 (10)
Psychology interventions	0 (0)	8 (6)
Delirium screening	0 (0)	1 (1)

ERM, early rehabilitation and mobilisation.

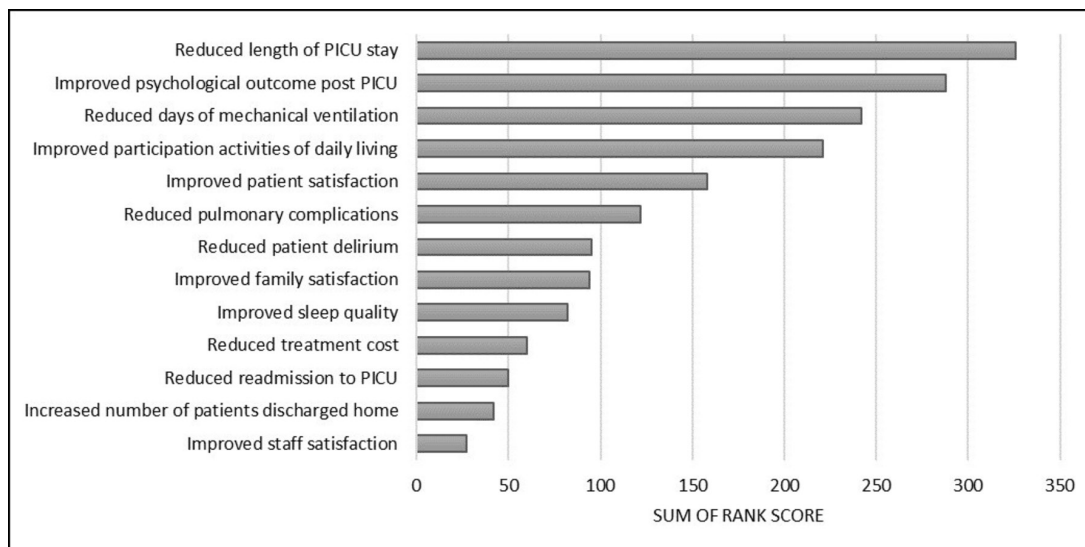


Figure 1 Perceived benefits of ERM: ranking of participants' potential top 5 perceived benefits of delivering ERM within PICUs. Sum of rank score: ranking of top 5 (1–5) (1st placed rank scored 5 points to 5th placed scored 1 point). 121/124 (98%) participants ranked scores. ERM, early rehabilitation and mobilisation; PICU, paediatric intensive care unit.

for patients after PICU, (3) reduced days of mechanical ventilation, (4) improved participation in activities of daily living and (5) improved patient satisfaction.

Table 4 Top 5 most important benefits of ERM

Perceived ERM benefits (most to least important)	Sum rank score*
Reduction in length of ICU stay	326
Improvement in the psychological impact of PICU care	288
Reduction in days requiring mechanical ventilation (MV)	242
Improvement in daily life participation following discharge	221
Improved patient satisfaction	158
Reduction in the rate of pulmonary complications	122
Reduction in patient delirium	95
Improved family satisfaction	94
Improvement in patient sleep quality	82
Reduction in treatment cost	60
Reduction in readmission	50
Increase in the number of patients discharged home	42
Improved staff satisfaction	27

*Sum of rank score: ranking of top 5 (1–5) (1st placed rank scored 5 points to 5th placed scored 1 point). 121/124 (98%) participants ranked scores.
ERM, early rehabilitation and mobilisation; ICU, intensive care unit; PICU, paediatric intensive care unit.

Initiation and delivery of ERM

The decision for ERM initiation was perceived by 96 (77%) to be primarily led by physiotherapists, 92 doctors (74%) and 64 bedside nurses (52%). Parents were felt to initiate ERM by only 24 of respondents (19%) (table 5).

The most influential factor in ERM initiation was reported to be patient stability (n=69, 56%). Other influential factors were the length of stay; 15 (12%) reported ERM was initiated within 24 hours, and 16 (13%) within 2–3 days of PICU admission. Only 5 (4%) of respondents would not consider ERM at all on PICU. The influence of perceived clinical stability is demonstrated in respondents' free-text comments:

We are involved as early as required depending on the child/young person medical stability and their rehabilitation needs. (Occupational Therapist, 033)

Table 5 Which professional or parent groups in PICU initiates ERM (n=124 respondents)

Professional or family group	Yes n (%)
Physiotherapists	96 (77)
Physicians	92 (74)
Bedside nurses	64 (52)
Senior nurses	58 (47)
Other members of the medical team	55 (44)
Occupational therapists	37 (30)
Parents or family members	24 (19)

ERM, early rehabilitation and mobilisation; PICU, paediatric intensive care unit.

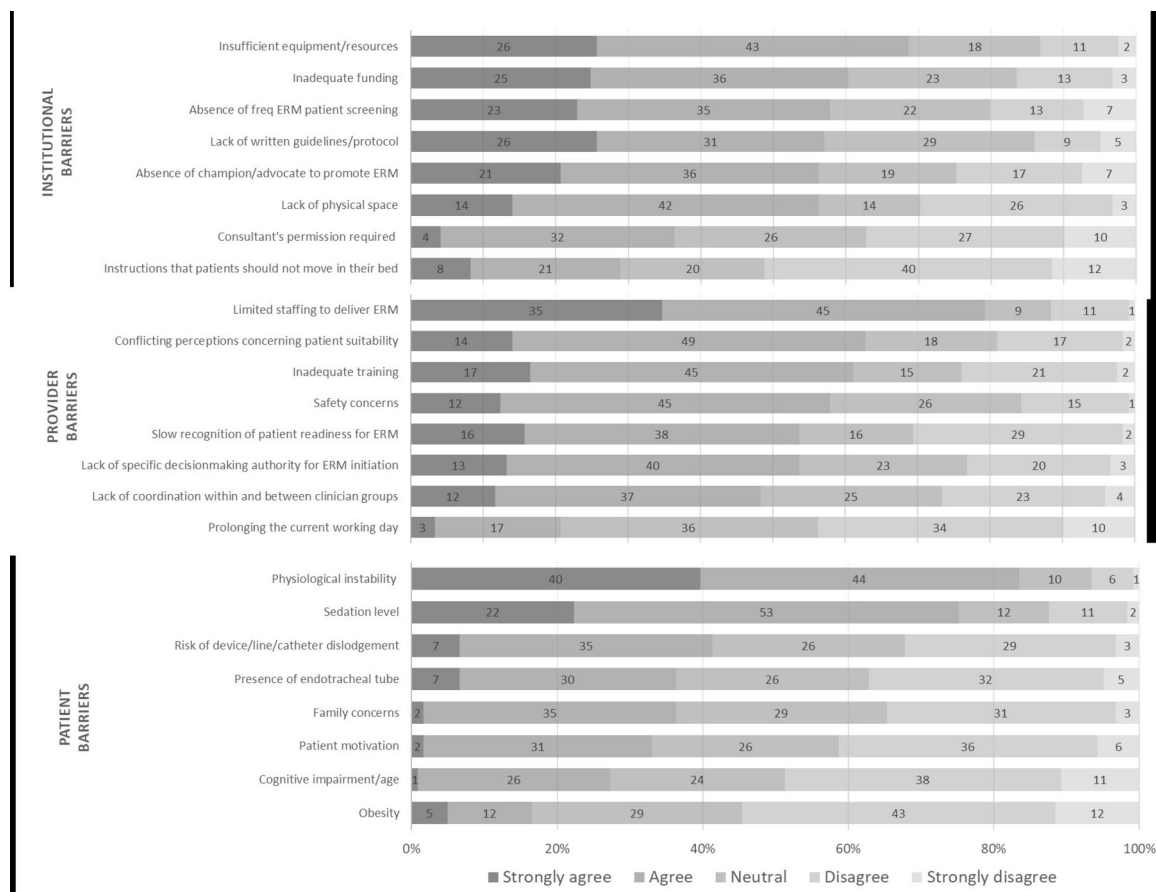


Figure 2 Perceived barriers of ERM: institutional, patients and provider barriers to ERM. The percentage of responses for categories strongly agree, agree, neutral, disagree and strongly disagree shown. Responses ranked on the cumulative score of percentage 'strongly agree and agree'. ERM, early rehabilitation and mobilisation.

Usually ERM activity is not considered until patients can physiologically tolerate movement and are cardiovascularly stable. (Nurse, 008)

Assessment of patient stability and tolerance of ERM was less well described. Most respondents ($n=98$, 79%) provided subjective cues or informal clinical criteria. These included monitoring vital signs, physiological changes, observing behavioural changes and documenting adverse events.

Physiotherapists ($n=113$, 92%), nurses ($n=103$, 84%) and parents or family members ($n=92$, 75%) were 'always' or 'very often' involved in the ongoing delivery of ERM with less frequent input from other members of the multidisciplinary teams (online supplemental material 2 and table 2).

Barriers to ERM implementation

Figure 2 presents the perceived barriers of ERM (see also online supplemental material 2 and table 3). The most significant barriers identified as institutional barriers were insufficient resources and equipment ('strongly agree' or 'agree': 83, 69%) and inadequate funding (73, 61%). Participants provided examples of resources having to be shared across organisations or specially ordered to deliver ERM to patients.

All equipment shared with the whole therapy department at present, therefore, dependent on availability. (OT, 010)

A lack of established protocols ($n=69$, 57%), ERM champions ($n=68$, 57%), space ($n=68$, 56%) and robust patient screening processes ($n=63$, 58%) were also issues identified by respondents. Most PICUs had access to standard lifting 22/26 (85%) and specialist static seating equipment 25/26 (96%); however, bedside or in-bed cycling machines were only available in 10 (38%) of PICUs (see table 6).

Limited staffing was the most frequently reported barrier to providers delivering ERM, with 101 (79%) 'agreeing' or 'strongly agreeing'. Approximately half of the respondents agreed that issues such as training, patient safety, lack of decision-making authority and delays in recognising patients' ERM needs were barriers to ERM initiation. However, only 25 (21%) 'agreed' or 'strongly agreed' that the impact of ERM potentially prolonging the working day was a barrier.

The two most frequently reported barriers to delivering ERM at the patient level were physiological instability ($n=101$, 81% agreeing or strongly agreeing) and sedation ($n=91$, 73%). Over 50% ($n=64$) 'disagreed' or 'strongly disagreed' that obesity was a barrier.

**Table 6** Types of ERM equipment available in each PICU (n=26)

ERM equipment available in each PICU	n (%)
Specialist static seating	25 (96)
Portable ventilators	23 (88)
Mobile lifts	22 (85)
Tilt table	22 (85)
Bed with full chair position	18 (69)
Specialist wheelchair	18 (69)
Bed with Trendelenburg features	13 (50)
Patient rolling walker	11 (42)
Bedside cycle or in-bed cycle	10 (38)
Ceiling lifts	8 (31)
Specialty bed with continuous side to side rotation	8 (31)
Bed with retractable footboard	7 (27)
Bed with chair egress exit out the foot of the bed	5 (19)
Transcutaneous electrical nerve stimulation	3 (12)

ERM, early rehabilitation and mobilisation; PICU, paediatric intensive care unit.

DISCUSSION

This national survey of healthcare practitioners from UK PICUs identified the importance of ERM as an intervention that participants believe can improve the physical and psychological recovery of critically ill or injured infants and children across all ages. Our findings indicate support for ERM but highlight uncertainty with suitability, variability with the definition of this complex intervention, variation in the timing of initiation and which patient groups should receive ERM. Key barriers to ERM delivery were identified (eg, funding and staffing) and potential clinical (eg, improved psychological outcomes) and economic (eg, reduced PICU length of stay) benefits to patients and PICUs were also identified.

How early is 'early' in ERM has been challenging to define for healthcare professionals? A time-based definition (eg, within the first 2–5 days of ICU admission) has been proposed¹⁷; however, this can conflict with the patient stability approach (eg, start as early as the patient is able to receive it). Our results indicate uncertainty and wide variation in time to start ERM (24 hours to over 7 days), increasing agreement for ERM to be considered after longer periods on PICU, and support for the concept of 'as early as the patient's clinical condition allows', which may be much longer. In the UK, only 43% of patients remain in PICU for 3 days or more.¹ The balance of delivering a programme of ERM to a large number of patients who may only receive intervention within a very short period versus targeting patients at a higher risk of prolonged PICU stay needs to be considered. However, it has been proposed that for ERM to

become embedded in clinical practice, it should become a standard of care within 48 hours of ICU admission.¹⁸

The uncertainty of the content of ERM also adds to the challenge for healthcare professionals to appreciate when ERM could be delivered. Understandably, routine bedside nursing care (eg, functional positioning) may be considered acceptable earlier than more advanced physical therapies requiring multiple staff (eg, sitting a ventilated child out of bed or in-bed cycling). Our survey identified clinical stability as the most influential patient factor for initiation. The reported lack of ERM protocols in most (21/26) UK PICUs reinforces a strong requirement for evidence-based standardised protocols with optimal timing, intensity, frequency and duration of ERM. There is a need for flexible protocols to allow for tailoring rather than prescription.

ERM was more likely to be delivered to patients admitted for greater than 28 days among patients with acquired brain injury or severe developmental delay across all age ranges. This reflects the cross-over between ERM and established rehabilitation programmes following acquired brain injury¹⁹ or for patients admitted to PICU with a pre-existing rehabilitation package. PICUs may be able to build on the success of established programmes to implement ERM to a wider critical care population and to use the existing multidisciplinary expertise, and evolving rehabilitation evidence base to support the adoption of effective treatments. To date, most published ERM intervention studies have excluded patients who were less than 3 years of age.^{4,6} However, this represents 60% of the UK PICU patient population,¹ and this age group was as likely to receive ERM as older children in our study. Future ERM trials should include all PICU age groups to ensure ERM content and efficacy is assessed across all potential patients.

Our results show that doctors, physiotherapists and nurses have an equally important role in the decision to initiate ERM within the UK NHS setting. This contrasts with other countries and healthcare settings where doctor-led approval was required by 70%–81% of respondents, which was a potential barrier to mobilisation.^{20,21} Nurses' and parents' roles are also important both in the initiation and delivery of ERM. In settings where nurses reported a low level (39%) of support for ERM, lack of involvement and understanding were key features.²² In our study, 91% felt 'involved' in the delivery of ERM. However, healthcare professionals reported that parents were the least likely group to initiate ERM (19%), although becoming influential in its ongoing delivery. This is consistent with recent European²³ and North American^{11,24,25} point prevalence studies in PICUs, highlighting the important role parents play in delivering ERM. Building on both the multidisciplinary support for ERM and empowering parents to initiate ERM may be potential strategies to improve implementation.

The key barriers to ERM practice were (1) at institutional level: insufficient resources, equipment and funding, (2) at provider level: limited staffing, training,

protocols and slow recognition of readiness for ERM and (3) at patient level: physiological instability, risk of endotracheal tube dislodgement and amount of sedation. These barriers have been previously described in other health settings^{20–22 26} with proposed facilitators, including adopting formal protocol/manual²⁷ (a key feature lacking across most UK PICUs), local champions²⁷ and team engagement/collaboration.^{27 28} Implementation of ERM within the NHS will require building on the established multidisciplinary teams, incorporating ERM within established protocols for weaning off mechanical ventilation and sedation and realistic goal setting. The potential benefits of ERM in terms of PICU length of stay and improvement in the psychological outcome for patients should be assessed within the core outcomes evaluating the efficacy of ERM within PICU.

The strength of this survey was an inclusive representation of 90% of UK PICUs and views from the wider multidisciplinary team. However, none or partial responses may indicate poor engagement in ERM topic, and as with all self-reported surveys, responses indicate reported rather than actual clinical practice. A limitation was the use of a non-validated questionnaire. We did not conduct questionnaire validation because it would be very difficult to standardise these questions within the time constraints of the study and the NIHR HTA funding. The study team considered the questionnaire suitable for the study aims after receiving two rounds of expert reviews. Finally, the findings represent the views of UK NHS staff and may not be generalisable to other healthcare settings.

CONCLUSION

ERM, in some form, is currently delivered to critically ill or injured patients of all ages across UK PICUs, but significant barriers to full implementation exist due to resource limitations and lack of institutional and national guidance. The UK should build on the existing strong multidisciplinary support for ERM in PICUs. A standardised protocol that sets out defined ERM interventions and implementation support to tackle modifiable barriers is required to ensure the delivery of high-quality ERM.

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Patient consent for publication Not applicable.

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REFERENCES

- PICANet. Paediatric Intensive Care Audit Network National Annual Report 2016 - 2018, 2019. Available: <https://www.picanet.org.uk/annual-reporting-and-publications/> [Accessed 15th Sep 2020].
- Lopes-Júnior LC, Rosa MADRdeP, Lima RAGde. Psychological and psychiatric outcomes following PICU admission: a systematic review of cohort studies. *Pediatr Crit Care Med* 2018;19:e58–67.
- Manning JC, Pinto NP, Rennick JE, et al. Conceptualizing post intensive care syndrome in Children-The PICS-p framework. *Pediatr Crit Care Med* 2018;19:298–300.
- Choong K, Awladthani S, Khawaji A, et al. Early exercise in critically ill youth and children, a preliminary evaluation: the WEECYCLE pilot trial. *Pediatr Crit Care Med* 2017;18:e546–54.
- Pun BT, Balas MC, Barnes-Daly MA, et al. Caring for critically ill patients with the ABCDEF bundle: results of the ICU liberation collaborative in over 15,000 adults. *Crit Care Med* 2019;47:3–14.
- Fink EL, Beers SR, Houtrow AJ, et al. Early Protocolized versus usual care rehabilitation for pediatric neurocritical care patients: a randomized controlled trial. *Pediatr Crit Care Med* 2019;20:540–50.
- Nydahl P, Sricharoenchai T, Chandra S, et al. Safety of patient mobilization and rehabilitation in the intensive care unit. systematic review with meta-analysis. *Ann Am Thorac Soc* 2017;14:766–77.
- National Institute for Health and Care Excellence. Rehabilitation after critical illness in adults [NICE guidance CG83], 2009. Available: <https://www.nice.org.uk/guidance/CG83> [Accessed 15th Sep 2020].
- Wieczorek B, Burke C, Al-Harbi A, et al. Early mobilization in the pediatric intensive care unit: a systematic review. *J Pediatr Intensive Care* 2015;2015:212–7.
- Cuello-Garcia CA, Mai SHC, Simpson R, et al. Early mobilization in critically ill children: a systematic review. *J Pediatr* 2018;203:25–33.
- Choong K, Zorko D, Awojoodu R, et al. P0071 / #1741: prevalence of acute rehabilitation for kids in the picu: a canadian multicenter point prevalence study (PARK-PICU Canada). *Pediatr Crit Care Med* 2021;22:68–9.
- Ista E, Redivo J, Kananur P, et al. ABCDEF bundle practices for critically ill children: an international survey of 161 PICUs in 18 countries. *Crit Care Med* 2022;50:114–25.
- Mayring P. Qualitative content analysis. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 2000;1. doi:<https://doi.org/10.17169/fqs-1.2.1089>
- Bengtsson M. How to plan and perform a qualitative study using content analysis. *NursingPlus Open* 2016;2:8–14.
- Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013;15:398–405.
- Burnard P. A method of analysing interview transcripts in qualitative research. *Nurse Educ Today* 1991;11:461–6.
- Hodgson CL, Berney S, Harrold M, et al. Clinical review: early patient mobilization in the ICU. *Crit Care* 2013;17:207.
- Cameron S, Ball I, Cepinskas G, et al. Early mobilization in the critical care unit: a review of adult and pediatric literature. *J Crit Care* 2015;30:664–72.
- Hayes L, Shaw S, Pearce MS, et al. Requirements for and current provision of rehabilitation services for children after severe acquired brain injury in the UK: a population-based study. *Arch Dis Child* 2017;102:813–20.
- Anekwe DE, Koo KK-Y, de Marchie M, et al. Interprofessional survey of perceived barriers and facilitators to early mobilization of critically ill patients in Montreal, Canada. *J Intensive Care Med* 2019;34:885066617696846.
- Choong K, Koo KKY, Clark H, et al. Early mobilization in critically ill children: a survey of Canadian practice. *Crit Care Med* 2013;41:1745–53.
- Wang J, Xiao Q, Zhang C, et al. Intensive care unit nurses' knowledge, attitudes, and perceived barriers regarding early mobilization of patients. *Nurs Crit Care* 2020;25:339–45.
- Ista E, Scholefield BR, Manning JC, et al. Mobilization practices in critically ill children: a European point prevalence study (EU PARK-PICU). *Crit Care* 2020;24:368.
- Curry A, Brown A, Williams S, et al. 1055: impact of an early mobility program in the hematologic oncologic PICU setting. *Crit Care Med* 2021;49:527.
- Kudchadkar SR, Nelliott A, Awojoodu R, et al. Physical rehabilitation in critically ill children: a multicenter point prevalence study in the United States. *Crit Care Med* 2020;48:634–44.
- Fontela PC, Forgiarini LA, Friedman G. Clinical attitudes and perceived barriers to early mobilization of critically ill patients in adult intensive care units. *Rev Bras Ter Intensiva* 2018;30:187–94.
- Goddard SL, Lorencatto F, Koo E, et al. Barriers and facilitators to early rehabilitation in mechanically ventilated patients—a theory-driven interview study. *J Intensive Care* 2018;6:4. eCollection 2018.
- Zheng K, Sarti A, Boles S, et al. Impressions of early mobilization of critically ill Children-Clinician, patient, and family perspectives. *Pediatr Crit Care Med* 2018;19:e350–7.

Supplementary Material File 1

PERMIT Online Survey



Paediatric Early Rehabilitation and Mobilisation during Intensive care (PERMIT) Survey

1. Introduction

Thank you for your interest in completing a questionnaire as part of the PERMIT Study.

Why have I been invited to take part?

You have been invited to take part because you are a health care practitioner responsible for the delivery of care to children in a PICU. We would like the views of a wide range of health care professionals, and you have been identified either through the collaborating Paediatric Intensive Care Society, Physiotherapy and Occupational therapy membership lists or recommended by lead clinicians in your institutions.

Study Overview

We are conducting research into Early Rehabilitation and Mobilisation (ERM) during paediatric critical illness in the UK and assessing the feasibility and design of a future clinical trial. ERM can encompass patient-tailored interventions or bundles of care provided within the critical care unit. Rehabilitation has been shown to improve quality of life and patient outcomes in the adult ICU; however, there is limited evidence in the PIC patient population and setting.

The whole PERMIT programme aims to assess key questions regarding the acceptability and feasibility of ERM in PIC and form recommendations for a future clinical trial to establish its effectiveness.

In this questionnaire, we would like to find out:

- What forms of ERM are provided in your PICs and to which patients;
- What resources are available (or could be available) to deliver ERM;
- Your views on evaluating ERM interventions;
- Whether you would be interested in a future clinical trial to assess ERM.

Thank you for your time (which we calculated should be less than 20 minutes) in completing this questionnaire.

Barney Scholefield & Jacqueline Thompson

On behalf of the PERMIT study team and the Paediatric Intensive Care Society -Study Group (PICS-SG)

2. A little demographic information about you please

1. Which hospital do you work at? *

Other (if not listed)

2. Which best reflects your current professional position? *

- Medical
- Nurse
- Physiotherapist
- Occupational therapist
- Speech and Language therapist
- Dietician
- Play therapist
- Psychologist
- Other (please specify):

3. Number of years experience working in PICU? *

- <1 year
- 1 to <5 years
- 5 to <10 years
- 10 to <15 years
- 15 to <20 years

More than 20 years

I do not work in PICU

Comments:

3. What ERM do you currently provide in your PICU?

In the following questions, we hope to explore your current practice related to early rehabilitation and mobilisation (ERM). We understand that the term ERM may mean different things to different professional groups; however, we are keen to capture the current diverse views and how ERM is defined by you and your PICU team.

4. Please describe in the box below the current ERM practice within your PICU. (We are especially interested in whether you provide anything that you feel fits within the term ERM, who receives ERM, what specific actions are involved in ERM and who delivers the ERM).

5. Which of the following best describes when you would consider ERM for a patient? *

Within 24 hours of admission to PICU

About 2 to 3 days after PICU admission

Around the end of the first week of PICU admission

Before discharge from PICU

As soon as the patient is stable enough

As soon as the patient is off mechanical ventilatory support

To start earlier than we historically considered starting rehabilitation and mobilisation

We do not consider ERM for our PICU patients

I don't know

Other (please specify):

Comments:

6. Which team members are involved in ERM in your PICU? (Please select how frequently they are involved. If the team member is not available in your PICU please select 'Not applicable')

	Always	Very often	Sometimes	Seldom	Never	Not applicable (as team member is not available in my PICU)	Don't know
Medical staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nursing staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Play therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients family or carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please define 'other' or add any comments

7. How often do patients, in general, receive ERM in your PICU?

	Always	Very often	Sometimes	Seldom	Never	Don't know
All PICU patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

8. How often do patients in the following age groups receive ERM in your PICU? (Please select an option for each)

	Always	Very often	Sometimes	Seldom	Never	Don't know
Infants & <1 year old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1-4 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
> 4-10 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
> 10-18 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

9. How often do patients within the following diagnostic categories receive ERM in your PICU? (Please select an option for each)

	Always	Very often	Sometimes	Seldom	Never	Don't know
Acquired brain injury patients (e.g. TBI, meningitis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sepsis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Congenital heart disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mechanically ventilated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Always	Very often	Sometimes	Seldom	Never	Don't know
Mechanically supported (e.g. ECMO)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory illness (bronchiolitis or pneumonia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Multi-organ failure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With pre-existing physical co-morbidity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With pre-existing severe developmental delay	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

10. How often do patients, with the following length of stay, receive ERM in your PICU? (Please select an option for each)

	Always	Very often	Sometimes	Seldom	Never	Don't know
Patients in PICU <3 days	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients in PICU 3-7 days	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients in PICU >7-28 days	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients in PICU >28 days	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

11. Who decides if the patient can start to receive ERM? (Please select all that apply)

- Medical consultant
- Other member of the medical team (e.g. PICU trainee/ advanced nurse practitioner)

- Bedside nurse
- Senior nurse on shift
- Physiotherapist
- Occupational therapist
- Parent(s)
- Don't know
- Not applicable
- Other (please specify):

Comments:

12. How does your PICU assess whether patients tolerate and cope with the therapy provided? (eg monitor safety)

13. Do you currently use or have an established guideline or protocol regarding management of ERM in your PICU?

- No
- Yes - if you are able to share, please email to b.scholefield@bham.ac.uk
- Don't know

Comments:

4. Question regarding your established ERM programme or protocol

14. What do you have within your protocolised ERM treatment? (Please select all that apply)

- Physical therapy not requiring additional equipment
- Physical therapy requiring additional equipment
- Occupational therapy
- Speech and language therapy
- Psychology
- Delirium screening
- We do not have a programme or protocol related to ERM activities
- Other (please specify):

Comments:

15. What are the key factors in successfully implementing your ERM protocol?

5. ERM related processes and equipment in your PICU

The following three questions are related to additional processes or equipment in your PICU related to ERM activities.

16. Does your PICU have a protocol or guidelines for the management of the following?

	Yes	No	Don't know
Sedation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Analgesia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug/ opioid withdrawal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Delirium	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	No	Don't know
Mobilisation (at any time point)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. What types of therapies or activities are available in your PICU? (Please select all that apply)

- Physical therapy - not requiring additional equipment (e.g. passive or active movements)
- Physical therapy - requiring additional equipment (e.g. in bed cycling)
- Occupational therapy
- Speech and language therapy
- Clinical psychology
- Delirium screening
- Patient diaries
- Play therapy
- Pet therapy
- Music therapy
- Other (please specify):

18. What equipment does your PICU have available for physical therapy/mobilisation? (Please select all that apply)

- Tilt table
- Bed with Trendelenburg features
- Bed with full chair position
- Bed with chair egress - exit out the foot of the bed
- Speciality bed with continuous side to side rotation
- Bed with retractable footboard i.e. flex a foot feature

- Mobile lifts
- Ceiling lifts
- Portable ventilators
- Patient rolling walker
- Bedside cycle (patient can remain in bed)
- Transcutaneous electrical stimulation of muscles
- Specialist wheelchair
- Specialist static seating i.e. tumble forms
- Other (please specify):

6. Preferences, barriers and outcomes

For the following questions, we would explore your strength of opinion on ERM as a therapy, potential barriers to using ERM in practice and which are the most important clinical outcomes to consider when assessing if ERM is beneficial.

19. Please select one option regarding your current views of ERM in your PICU? *

- Crucial, should be the top priority in the care of PICU patients
- Very important, should be a priority in the care of PICU patients
- Important, should be a priority in the care of PICU patients
- Somewhat important, should be considered in the care of PICU patients
- Not of great importance, clinicians should bear it in mind in the care of PICU patients
- Of minimal importance to the care of PICU patients
- Of no importance to the care of PICU patients

Comments:

20. Below are potential institutional barriers to the delivery of ERM. Please select to what extent you agree/disagree that each are barriers to delivery of ERM in your PICU. *

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Instructions that patients should not move in their bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consultant's permission or prescription is required prior to mobilisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Insufficient equipment/resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate funding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of written guidelines/ protocol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of physical space	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Absence of champion/ advocate to promote ERM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Absence of frequent (e.g. daily) ERM patient screening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

21. Below are potential patient barriers to the delivery of ERM. Please select to what extent you agree/disagree that each are barriers to delivery of ERM in your PICU. *

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Physiological instability ('the patient is just too sick')	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Sedation level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Presence of endotracheal intubation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk of device/ line/ catheter dislodgement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive impairment/ age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Obesity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient motivation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

22. Below are potential provider barriers to the delivery of ERM. Please select to what extent you agree/disagree that each are barriers to delivery of ERM in your PICU. *

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Lack of prioritisation of ERM within patient care plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limited staffing to deliver ERM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of coordination within and between clinician groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Slow recognition of patient readiness for ERM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conflicting perceptions concerning patient suitability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Safety concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of specific decision-making authority for ERM initiation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prolonging the current working day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

23. Please rank what you perceive to be the top 5 most important benefits that ERM could provide in PICU. (Please select, in order, the top perceived benefits by selecting a box). *

	1 (most important)	2	3	4	5 (least important)
Reduction in treatment cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduction in patient delirium	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduction in length of ICU stay	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduction in days requiring mechanical ventilation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduction in the rate of pulmonary complications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduction in readmission (hospital and PICU)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increase in number of patients discharged home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improved patient satisfaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	1 (most important)	2	3	4	5 (least important)
Improved staff satisfaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improved family satisfaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improvement in patient sleep quality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improvement in psychological impact of PICU care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improvement in daily life participation following discharge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

7. Final thoughts

24. Would you be willing to support a future clinical trial in the UK and Ireland based on evaluating ERM practice?

- Yes
- No
- Don't Know

Comments:

25. Would you allow us to contact you in the future with information regarding workshops we will be running to discuss ERM practice and trial feasibility, please? *

- Yes (please click the link on the next page to provide best contact information, thank you!)
- No

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Supplementary Material File 2

Table 1: Descriptions of ERM

Category	Sub-categories	Examples:
<p>Activity-focused ERM is activity-focused, with consideration of seating and equipment, primarily delivered by nursing and allied health care professionals with optimised sedation management to promote patient engagement. There is a lack of consensus on what is routine care compared with purposeful ERM activity.</p>	Activity – mobilising, positioning, stretching	<p>“ERM provided includes - passive movements of limbs, periodic change of position, use of splints on extremities and if stable in the long term patients - sitting up in tumble form chair and mobilising out of bed.” (Doctor, 67)</p> <p>“We aim to get the children sitting upright, either over the edge of the bed or inappropriate seating as soon as possible.” (Occupational Therapist, 001)</p> <p>“Nursing staff are taught the importance of regular position changes for patient ... and positioning to maintain ranges of movement and prevent foot drop.” (Nurse, 017)</p>
	Core health care professional involvement – physiotherapist, nurse, occupational therapist	<p>“We try and mobilise patients as soon as able when not invasively ventilated - physio led.” (Doctor, 058)</p> <p>“As physiotherapists, we work with the occupational therapist and nursing staff to either re-position, sit up in bed, sit on the edge of the bed or stand whilst on the ventilators.” (Physiotherapist, 069)</p>
	Additional health care professional involvement – psychology, dietician, play therapist, speech and language therapists	<p>“Speech and language therapy become involved usually when nursing or medical staff identify a need for referral.” (Doctor, 003)</p> <p>“We have a Play Specialist on PICU, who assists with communication tools/toys.” (Nurse, 082)</p>
	Seating and equipment	<p>“Specialist seating need – linking in with OT to ensure appropriate seating available.” (Physiotherapist, 019)</p>

		“We have also in the past asked adult [services] to use their moto-med bike and used this with teenagers, but this can be a challenge as it is very far from PICU and it is often in use.” (Physiotherapist, 014)
	Sedation management	“Working with the medics to wean sedation as quickly as possible. This promotes faster ability to mobilise and progress in their rehabilitation.” (Nurse, 034)
	‘Routine care’ vs ‘purposeful ERM package’	Some centres define ERM as passive range of movement, repositioning or providing splints. We would deem this as essential core cares rather than ERM; the large majority of our patients will have positioning and movement plan from day 1 of admission.” (Physiotherapist, 111)
Tailored Following the assessment of needs and patient and family preference, ERM activities are personalised to the individual patient.	Assessment of need	“We have a programme where patients are categorised to one of 3 levels. Each level provides nursing and therapy staff with activities aligned to the acuity of the patient.” (Nurse, 040)
	Individual preference	“Parents will tell us what their child enjoys doing and make suggestions, often provide toys/games from home.” (Nurse, 076) “Discuss with parents what patient enjoys doing, watching etc. Discuss options regarding taking patients ‘out’ where possible if long term patients.” (Nurse, 015)
Promote recovery The purpose of ERM is to normalise the PICU environment, to create an environment that addresses holistic needs, sustains or promotes development and supports recovery from critical illness.	Normalising PICU environment	“Provide activities they would use for their enjoyment. This enables them to be more relaxed and less aware of what is going on with / around them.” (Play specialist, 102) “Being in PICU can be a frightening experience. Not only is a child/young person away from home, but also away from their usual environment, family and friends. There are unfamiliar sounds, smells, equipment and people. The play specialist can help to make the stay much more enjoyable and children/young people to cope and understand.” (Play specialist, 055)
	Sustain / promote child development	“Encouraging the patient to regain or further their development in a therapeutic fun manner.” (Play therapist,102)

	Restoration / recovery	“Interventions aim to promote physical recovery – movement, and ability to engage in activities and psychological recovery – orientation, speech, ability to play and attend school. “ (Nurse, 021)
Timing of ERM The optimal timing of ERM initiation is challenging for health care professionals to define, although likelihood perceived to increase with increased length of stay. Influenced by the perceived stability of patients and the balance of risk to benefit.	‘Early’ poorly defined	<p>“I like to think we consider it within 2-3 days we have a better idea of the patients PICU journey and how long they are going to stay. The reality is it’s usually longer... usually week 2 of admission if they are still on the unit.” (Physiotherapist, 090)</p> <p>“There is no formal plan for who decides if a patient should start ERM and when... Currently the delivery of ERM is fairly ad hoc, based on what is highlighted from daily handover each morning.” (Physiotherapist, 083)</p> <p>“We provide ERM as a structured programme... every patient after 24 hours of admission is considered for ERM.” (Doctor, 012)</p>
	Patient stability, risk and benefit	<p>“Members of the PICU team with less experience of early rehab can deem ERM ‘unsafe’ which can occasionally act as a barrier.”(Physiotherapist, 016)</p> <p>“Usually ERM activity is not considered until patients can physiologically tolerate movement and are stable with observations.” (Nurse, 008)</p>
	‘Long-stay’	<p>“ERM is often thought about as a patient comes up to extubation or has failed extubation, and we feel that the reason for failure may be because of critical care weakness.” (Physiotherapist, 031)</p> <p>“We provide very little ERM on PICU, other than for long term patients, which is often, in my opinion, delayed.” (Nurse, 007)</p>

Table 2: Reported frequency of receiving or being involved in Early Rehabilitation and Mobilisation by age groups, length of PICU stay, diagnostic category, and health care professional or parental/family role (n=124 respondents)*

By age group	Always (n, %)	Very often (n, %)	Sometimes (n, %)	Seldom (n, %)	Never (n, %)	Don't know (n, %)	Not Applicable# n
All PICU Patients (any age)	6 (5)	45 (36)	48 (39)	14 (11)	0 (0)	11 (9)	0
>10-18 years old	18 (15)	40 (32)	43 (35)	8 (6)	1 (1)	14 (11)	0
>4-10 years old	16 (13)	42 (34)	41 (33)	10 (8)	1 (1)	14 (11)	0
1-4 years old	13 (10)	42 (34)	39 (31)	13 (10)	1 (1)	16 (13)	0
Infants & <1 year old	6 (5)	47 (38)	32 (26)	20 (16)	3 (2)	16 (13)	0
By length of stay in PICU							
PICU >28 days	43 (35)	48 (39)	14 (11)	4 (3)	0 (0)	15 (12)	0
PICU >7-28 days	27 (22)	46 (37)	26 (21)	8 (6)	0 (0)	17 (14)	0
PICU 3-7 days	12 (10)	32 (26)	40 (32)	19 (15)	5 (4)	16 (13)	0
PICU <3 days	3 (2)	14 (11)	39 (31)	33 (27)	17 (14)	18 (15)	0
By diagnostic category							
Acquired brain injury	36 (29)	39 (31)	16 (13)	11 (9)	4 (3)	18 (15)	0
Severe developmental delay	11 (9)	43 (35)	39 (31)	12 (10)	3 (2)	16 (13)	0
Cancer	11 (9)	24 (19)	36 (29)	14 (11)	4 (3)	35 (28)	0
Pre-existing physical morbidity	9 (7)	38 (31)	44 (35)	12 (10)	4 (3)	17 (14)	0
Mechanically ventilated	9 (7)	38 (31)	39 (31)	18 (15)	5 (4)	15 (12)	0
Congenital heart disease	9 (7)	24 (19)	39 (31)	15 (12)	6 (5)	31 (25)	0
Respiratory illness	7 (6)	35 (28)	39 (31)	22 (18)	3 (2)	18 (15)	0
Sepsis	7 (6)	28 (23)	44 (35)	20 (16)	5 (4)	20 (16)	0
Multi-organ failure	5 (4)	14 (11)	32 (26)	35 (28)	12 (10)	26 (21)	0
Mechanically supported (e.g. extracorporeal life support)	4 (3)	8 (6)	14 (11)	13 (10)	47 (38)	38 (31)	0
Health Care Professional team members & parent or family member(s) involvement in ERM (when applicable#)							
Physiotherapist	86 (70)	27 (22)	4 (3)	2 (2)	0 (0)	4 (3)	1

Nurse	54 (44)	49 (40)	9 (7)	5 (4)	0 (0)	6 (5)	1
Parent or family member	36 (29)	56 (46)	19 (15)	7 (6)	1 (1)	4 (3)	1
Occupational therapist	23 (19)	34 (29)	29 (24)	20 (17)	6 (5)	7 (6)	5
Doctor	22 (18)	20 (16)	26 (21)	30 (24)	13 (11)	12 (10)	1
Play therapist	12 (10)	24 (21)	39 (34)	26 (23)	9 (8)	5 (4)	9
Dietician	10 (8)	20 (17)	12 (10)	29 (24)	37 (31)	13 (11)	3
Speech and Language therapist	4 (3)	11 (9)	40 (33)	35 (29)	20 (17)	10 (8)	4
Psychologist	3 (3)	11 (10)	24 (23)	32 (30)	30 (28)	6 (6)	18

* Percentages may not total 100 due to rounding

Not applicable (e.g. not available in PICU) responses excluded from percent calculation.

Table 3: Barriers of ERM delivery within Paediatric Intensive Care Units (n=124 respondents)*

	Strongly Agree n (%)	Agree n (%)	Neutral n (%)	Disagree n (%)	Strongly Disagree n (%)	Skipped responses[#] (n)
Institutional barriers						
Insufficient equipment/resources	31 (26)	52 (43)	22 (18)	13 (11)	3 (2)	3
Lack of written guidelines/protocol	31 (26)	38 (31)	35 (29)	11 (9)	6 (5)	3
Inadequate funding	30 (25)	43 (36)	28 (23)	16 (13)	4 (3)	3
Absence of champion/advocate to promote ERM	25 (21)	43 (36)	23 (19)	21 (17)	9 (7)	3
Absence of frequent ERM patient screening	25 (23)	38 (35)	24 (22)	14 (13)	8 (7)	14
Lack of physical space	17 (14)	51 (42)	17 (14)	32 (26)	4 (3)	3
Instructions that patients should not move in their bed	10 (8)	25 (21)	24 (20)	48 (40)	14 (12)	3
Consultant's permission or prescription is required prior to mobilisation	5 (4)	39 (32)	32 (26)	33 (27)	12 (10)	3
Provider barriers						
Slow recognition of patient readiness for ERM	19 (16)	46 (38)	19 (16)	35 (29)	2 (2)	3
Limited staffing to deliver ERM	42 (35)	54 (45)	11 (9)	13 (11)	1 (1)	3
Lack of prioritisation of ERM within patient care plans	27 (22)	45 (37)	22 (18)	24 (20)	3 (2)	3
Inadequate training	20 (17)	54 (45)	18 (15)	26 (21)	3 (2)	3
Conflicting perceptions concerning patient suitability	17 (14)	59 (49)	22 (18)	21 (17)	2 (2)	3
Lack of specific decision-making authority for ERM initiation	16 (13)	49 (40)	28 (23)	24 (20)	4 (3)	3
Safety concerns	15 (12)	55 (45)	32 (26)	18 (15)	1 (1)	3
Lack of coordination within and between clinician groups	14 (12)	44 (37)	30 (25)	27 (23)	5 (4)	4
Prolonging the current working day	4 (3)	21 (17)	43 (36)	41 (34)	12 (10)	3
Patients barriers						
Levels of physiological instability	48 (40)	53 (44)	12 (10)	7 (6)	1 (1)	3
Sedation level	27 (22)	64 (53)	15 (12)	13 (11)	2 (2)	3
Presence of endotracheal intubation levels	8 (7)	36 (30)	32 (26)	39 (32)	6 (5)	3
Risk of device/line/catheter dislodgement levels	8 (7)	42 (35)	32 (26)	35 (29)	4 (3)	3
Cognitive impairment/age levels	1 (1)	32 (26)	29 (24)	46 (38)	13 (11)	3
Obesity levels	6 (5)	14 (12)	35 (29)	52 (43)	14 (12)	3

Patient motivation level	2 (2)	38 (31)	31 (26)	43 (36)	7 (6)	3
Family concerns levels	2 (2)	42 (35)	35 (29)	38 (31)	4 (3)	3

* Percentages may not total 100 due to rounding # Skipped responses excluded from percent calculation.