Paediatric Intensive Care follow-up provision in the UK and Republic of Ireland

Manuscript type: Evaluation

Running header: PICU follow-up provision in the UK and RoI

Key words: Follow-up; Paediatric Intensive Care; survey; Post Intensive Care Syndrome-pediatrics.

Authors:

Joseph C. Manning, RN, PhD^{1,2*}

Barnaby R. Scholefield MBBS, PhD^{3,4}

Emma Popejoy RN, PhD^{1,2}

Elizabeth Dodds, RN, MNursSci (Hons)⁵

Jos M. Latour RN, PhD^{6,7}

1. Nottingham Children's Hospital, Nottingham University Hospitals NUS Trust, Nottingham, UK
2. Children and Young People's Health Research, School of Health Sciences, The University of Nottingham, Nottingham, UK.
3. Birmingham Acute Care Research Group, Institute of Inflammation and Ageing, University of Birmingham, Birmingham, UK
4. Paediatric Intensive Care Unit, Birmingham Children's Hospital, Birmingham, UK
5. Paediatric Intensive Care Unit, Nottingham Children's Hospital, Nottingham University Hospitals NUS Trust, Nottingham, UK

6. School of Nursing and Midwifery, Faculty of Health: Medicine, Dentistry and Human Sciences, University of Plymouth, UK.
7. Nursing Department, Children's Hospital of Fudan University, Shanghai, People's Republic of China.

Corresponding Author:

Dr Joseph Manning, Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust, Queens Medical Centre Campus, Derby Road, Nottingham, NG7 2UH, UK.

joseph.manning@nottingham.ac.uk

Copyright disclosure:

Dr Manning institution received funding from CLAHRC East Midlands. Dr Scholefield, Dr Popejoy, Ms Dodds and Professor Latour disclosed that they do not have any potential conflicts of interest.

Conflict of Interest statement:

The authors do not have any conflicts of interest to disclose.

Author Contribution statement:

Dr Manning was the lead investigator for the study. Dr Manning, Dr Scholefield and Professor Latour conceptualised and designed the study. Dr Manning and Ms Dodds collected the data. All authors contributed to data analysis, drafting the manuscript, gave approval of the final version to be published, and agreed to be accountable for all aspects of the work.

Funding:

This study was funded by CLAHRC East Midlands as part of a Midlands and East Clinical Gold (post-doctoral) Scholarship to Dr Joseph Manning. The funder was not involved in the design, execution, analysis and writing up of the study.

Acknowledgements:

We would like to acknowledge the following: Dr Cilia Kjer (Department of Anaesthesia, Zealand University Hospital, Denmark) for permission to use the follow-up after intensive care treatment survey and undertaking the initial translation of the survey from Danish to English; the team that supported the UK validation of the survey with particular thanks to Drs Lyvonne Tume and Gillian Colville; The Paediatric Intensive Care Society Study Group (PICS-SG) for endorsing the study and supporting the mail out of the survey; and to all the clinicians that took the time to participate in the study.

Word Count: 2035 words (excluding reference list)

1 **Abstract**

2 **Objective**

3 To examine the characteristic, content and role of Paediatric Intensive Care Units (PICUs) in
4 the provision of follow-up for children and their families' post-intensive care discharge in the
5 United Kingdom and Republic of Ireland.

6 **Design**

7 Descriptive self-reported, web-based survey design.

8 'In-hospital PICU follow-up' was defined as follow-up delivered by the PICU team following
9 PICU discharge but before hospital discharge and 'post-discharge PICU follow-up' was
10 defined as follow-up delivered by the PICU team following hospital discharge.

11 **Setting**

12 Survey administered to all 28 PICUs in the United Kingdom and Republic of Ireland.

13 **Participants**

14 Pediatric Intensive Care medical directors or delegated individual.

15 **Measurements and main results**

16 Data were collected between September 2017-January 2018 with a response rate of 79%
17 (n=22/28). Twelve units provided either in-hospital and/or post-discharge PICU follow-up.
18 Ten (45%) PICUs reported providing in-hospital follow-up, with half (n=5) using an eligibility
19 criteria for in-hospital follow-up which related to disease groups. The most frequently
20 reported form of in-hospital PICU follow-up consisted of face-to-face patient consultation
21 (n=8) by a PICU doctor (n=5) and/or nurse (n=4). The time at which initial contact was made

was usually not pre-determined (n=4) and the care needs assessed included: tracheostomy care (n=4); respiratory care (n=4); and sedative medication weaning plan (n=5). Four PICUs reported to provide post-discharge follow-up. This involved telephone (n=2), follow-up clinic consultations (n=1) or home visits (n=1), provided predominantly by PICU doctors (n=2), with their activity directed by patient needs (n=3).

Conclusions

Despite increasing evidence to suggest PICU survivors and their families experience negative sequelae post-PICU discharge, less than half of PICUs surveyed provide in-hospital follow-up and only a minority provide post-discharge follow-up. There is variation in the delivery, content and format of in-hospital and post-discharge PICU follow-up in the United Kingdom and Republic of Ireland.

33 Introduction

34 Globally the numbers of children that survive critical illness are at an all-time high [1].
35 However, evidence suggests that critical illness can cause iatrogenic harm due to treatment
36 and environmental factors [2, 3]. As such, for some children and their families, transitioning
37 out of the Paediatric Intensive Care Unit (PICU) to longer-term survival may result in physical
38 deconditioning, cognitive impairment, as well as emotional and social adversities [4-11].

39 Evidence suggests the presence of post-traumatic stress and psychopathology in families of
40 children admitted to the PICU [12]. A recent literature highlights a dearth of studies about
41 follow-up care for parents of children admitted to the PICU, but recognises that the existing
42 literature demonstrates that some form of follow-up is beneficial in relation to parental
43 wellbeing [13]. Parents have also commented that follow-up after their child's PICU
44 admission would have been valuable for them, particularly for those who had higher levels of
45 stress during their child's admission [14]. Additionally, some research has begun to try to
46 identify which children are at increased risk of psychiatric symptoms post-discharge, and
47 suggests that acute inflammation during PICU admission is associated with psychopathology
48 following discharge [15]. Further research in the field may enable the identification of those
49 families at greatest risk of physical and psychological sequelae and ensure that targeted
50 PICU follow-up is implemented, thus reducing the impact of such PICU associated morbidity.

51 Despite national guidance for adults that experience critical illness and require admission to
52 intensive care, which asserts that follow-up should be provided as a way to meet patients'
53 psychological needs and improve the quality of their recovery [16], similar guidance within
54 paediatrics is lacking. In addition to a lack of guidance, barriers to the provision of intensive
55 care follow-up are reported to include deficits in the evidence to demonstrate its
56 effectiveness and the subsequent allocation of adequate resources [17]. However, other
57 authors have described that the provision of intensive care follow-up services requires only
58 modest resources [18, 19]. Despite this, there is a growing body of literature in the field has

resulted in an increased recognition that surveillance and intervention to monitor and optimise outcomes of children and families beyond the PICU is required [20, 21, 22]. Despite this, the characteristics, content and role of the PICU team in the provision of follow-up in the UK and RoI is currently unclear.

This study aimed to: (i) determine the characteristics and content across the United Kingdom (UK) and Republic of Ireland (RoI) in relation to in-hospital and post-discharge PICU follow-up; and (ii) evaluate clinicians' perceptions of the importance of PICU follow-up provision. For the purpose of this study the term 'in-hospital PICU follow-up' was defined as follow-up delivered by the PICU team following PICU discharge but before hospital discharge, and 'post-discharge PICU follow-up' was defined as follow-up delivered by the PICU team following hospital discharge.

Methods

Design

We undertook a cross-sectional, web-based survey. As this was classified as a service evaluation, governance approvals were provided by Nottingham University Hospitals NHS Trust (Ref: 17-207c). The study protocol was peer reviewed and endorsed by the Paediatric Intensive Care Society Study Group (PICS-SG) in the UK.

Sample/Procedure

All PICUs in the UK and RoI (n=28) were invited to participate in the study. Initial email contact to PICU medical directors/lead clinicians was made via the Paediatric Intensive Care Society in September 2017, which included study information and a hyperlink to the survey. Two email reminders were sent to non-responders in October and November 2017. The investigator telephoned remaining non-responders in January 2018. PICU medical directors

or a delegated individual were deemed as knowledgeable about the services their PICU teams provided and were therefore requested to complete the survey.

Measure

An adapted version of the 'Follow up after intensive care treatment survey' developed in Denmark was used [23]. For adaption to the UK/RoI, the questionnaire was translated from Danish to English, by the primary author (Dr Kjer) of the initial survey. Face validity and wording of the questionnaire was then assessed by a UK panel of PICU experts including paediatric intensivists, nurses, clinical psychologist, and physiotherapists, with the final questionnaire being piloted by the expert team and the investigators (n=8). The questionnaire consisted of four sections: in-hospital PICU follow-up; post-discharge PICU follow-up; clinician perceptions of PICU follow-up and future developments; and demographic variables (Electronic Supplementary File 1). The web-platform Jisc Online Survey® was used to distribute the survey (DOI: 10.13140/RG.2.2.28561.17763).

Data analysis

Descriptive statistics were used to describe and summarize the quantitative variables and the categorical data were described using frequencies and percentages. Free text responses were extracted, summarised and included in the reporting to add detail to the descriptive statistics.

Results

Twenty-two PICUs completed the survey, resulting in a response rate of 79% with representation from all five nations of the UK and the RoI. Among the 22 units that participated, twelve units (54%) reported offering either in-hospital (45%, n=10) or post-discharge PICU follow-up (18%, n=4), with two (9%) offering both.

In-hospital PICU-follow-up

For the 10 units that reported delivery of in-hospital PICU follow-up, a summary of the activity characteristics and content is presented in Table 1. Only four PICUs had a procedure, guideline or policy for in-hospital follow-up; two units had a specific criteria for children that received in-hospital follow-up; and three had a standardised checklist. The main form of contact was face to face consultation (80%, n=8), with time to contact varying from 24-48 hours (n=3), to seven days after PICU admission (n=1), or not pre-determined (n=4). In-hospital PICU follow-up was provided predominantly by medical or nursing personnel and involved assessment of care needs pertaining to tracheostomy care (n=4), respiratory care including CPAP and suction (n=4), and medication weaning plan (sedation and withdrawal) (n=5).

For the 12 PICUs who reported non-delivery of in-hospital follow-up, the main reasons for non-provision were: not enough staff (n=9); too few financial resources (n=9); and patients' speciality teams address any follow-up needs (n=6).

Post-discharge PICU-follow-up

Four (18%) of the 22 PICUs offered post-discharge follow-up, with the main characteristics and content summarised in Table 2. None of the PICUs had a policy, guideline or procedure for follow up activity. Two units had a criteria for selecting those who would receive post-discharge PICU follow-up that included: families of children who had died (n=1) and certain disease/treatment groups that included neuro-trauma, receipt of ECMO, and long-term ventilation (n=1). Forms of contact for post-discharge follow-up included telephone consultation (n=2), clinic (n=1) or home visit (n=1), with the time to contact varying according to patient (n=2) or specified by the unit as 1 to <3 months post PICU discharge (n=2). Post-discharge PICU follow-up was provided by a range of professionals from the multi-disciplinary team and the activity was dependent on case by case basis (Table 2).

130

131 The main reasons given for non-provision of post-discharge follow-up by the remaining 18
132 PICUs were: patients' needs are met by other services (n=10); not enough staff (n=5); too
133 few resources (n=6); and unclear of the benefits of providing post-discharge follow-up (n=5).

134 **Perceptions and plans of PICU follow-up**

135 Eighty-two percent (n=18) of the PICU respondents totally agreed that in-hospital follow-up
136 was important after a child's admission to PICU (Table 1). This was in comparison to only
137 45% (n=10) of PICU's who totally agreed that post-discharge follow-up was important (Table
138 2). Despite this, no PICU respondents totally disagreed that either in-hospital or post-
139 discharge PICU follow-up was important.

140 **Discussion**

141 Despite growing awareness of the morbidities associated with PICU survival [4], this national
142 study demonstrates that Paediatric Intensive Care led follow-up in the UK, whether that be
143 in-hospital or post-hospital discharge, is not consistently delivered. Our findings illuminate
144 that differences in follow-up services exist, however the impact of such variance is unknown.
145 For those PICUs that are providing follow-up, the majority do so without evidence-based
146 protocols or guidelines to direct activity. Furthermore, in the UK and RoI the provision of
147 post-hospital discharge PICU led follow-up services is scant. These results are set in a
148 context where the focus of the PICU services over the past 20 years has been centralisation
149 and standardisation in order to improve quality and survival [24-26]. Therefore, this could be
150 interpreted as surprising. However, this finding could be attributable, in part, to current
151 national guidance on the provision of follow-up for patients surviving critical illness relating
152 only to the adult [27]. Furthermore, the considerable variation in the characteristics and
153 content of follow-up practices could also be ascribed to the lack of research identifying those
154 with morbidities, when follow-up is required, and what intervention and monitoring is

required. The development of guidance regarding the content, timing and targeting of PICU follow-up services necessitates further research in order to determine the characteristics of the children and families most in need of follow-up support, their specific needs and the preferred mode of delivery.

Paediatric Intensive Care Units that responded to this survey were not unanimous in their perceptions of the importance of in-hospital or post-discharge PICU follow-up. This could have been informed by perceived deficits in resources, the evidence base, and clinician readiness to undertake follow-up [28]. However, this appears incongruent with the needs and expectations of patients, the public and wider stakeholders [29,30]. These perceptions may present a significant barrier to the provision of follow-up care, and consequently the achievement of optimal physical and psychosocial wellbeing for the child and their family. Therefore these clinician related barriers to PICU follow-up need to be further investigated and addressed.

The strengths of this study are that it achieved a good response rate of 79% of PICUs in the UK and RoI. Representation was achieved from all of the countries within the UK and RoI and covered all geographical areas. Limitations include that PICUs were represented by only one member of staff who may lack awareness of some of the services provided and may not be representative of the whole PICU. Additionally their perceptions about the importance of in-hospital and post-discharge follow-up may not adequately reflect that of the PICU team as a whole.

In conclusion, this survey has identified variation in the delivery, content and format of follow-up provided to PICU survivors in the UK and RoI, with a distinct paucity in provision of post-discharge follow-up. Further research that is warranted is twofold: to examine the characteristics, content and role of PICU follow-up across healthcare contexts to allow for international comparison; and to generate new knowledge on survivor outcomes and their

180 trajectories in order to build the evidence to direct follow up care, which optimises child and
181 family outcomes.

182

183

What is known about the subject

- Surviving childhood critical illness/injury can impact on health outcomes for the child and their family.
- In the UK there is national guidance for the provision of follow-up for adults that survive critical illness/injury, however there is no equivalent guidance for survivors of paediatric intensive care.
- In the UK and Republic of Ireland it is unclear what PICU follow-up is provided to children and their families who survive critical illness.

What this paper contributes

- This study has identified variation in the delivery, content and format of follow-up provided to PICU survivors in the UK and Republic of Ireland.
- There is a distinct paucity in PICU provision of post-discharge follow-up to children and families.

184

References

1. Namachivayam P, Shann F, Shekerdemian L, et al: Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward. *Pediatr Crit Care Med* 2010, 11(5), pp 549-555
2. Watson RS, Asaro LA, Hutchins L, et al: Risk factors for functional decline and impaired quality of life after pediatric respiratory failure. *Am J Respir Crit Care Med* 2019, 200(7), pp 900-909
3. Choong K: PICU-acquired complications: the new marker of the quality of care. *ICU Manag Pract* 2019, 19(2), pp 85-88
4. 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(4), pp 298-300
5. Shudy M, de Almeida ML, Ly S, et al: Impact of pediatric critical illness and injury on families: a systematic literature review. *Pediatrics* 2006, 118 Suppl 3(Supplement 3), pp S203-218
6. Suleman Z, Evans C, Manning JC: Parents' and carers' experiences of transition and aftercare following a child's discharge from a paediatric intensive care unit to an in-patient ward setting: A qualitative systematic review. *Intensive Crit Care Nurs* 2019, 51, pp 35-44
7. Watson RS, Choong K, Colville G, et al: Life after Critical Illness in Children—Toward an Understanding of Pediatric Post-intensive Care Syndrome. *J Pediatr* 2018, 198, pp 16-24
8. Banwell BL, Mildner RJ, Hassall AC, et al: Muscle weakness in critically ill children. *Neurology* 2003, 61(12), pp 1779-1782
9. Choong K, Al-Harbi S, Siu K, et al: Functional recovery following critical illness in children: the "wee-cover" pilot study. *Pediatr Crit Care Med* 2015, 16(4), pp 310-318

10. Pinto NP, Rhinesmith EW, Kim TY, et al: Long-Term Function After Pediatric Critical Illness: Results From the Survivor Outcomes Study. *Pediatr Crit Care Med* 2017, 18(3), pp e122-e130
11. Du Pont-Thibodeau G, La K, Francois T, et al. "367: Outcomes After Pediatric Intensive Care: First-Year Experience Of A Picu Follow-Up Clinic." *Critical Care Medicine* 2020, 48(1): 165.
12. Rodriguez-Rey R and Alonso-Tapia J. "Relation between parental psychopathology and posttraumatic growth after a child's admission to intensive care: Two faces of the same coin?" *Intensive Crit Care Nurs* 2017, 43: 156-161.
13. Bedford ZC and Bench S "A review of interventions supporting parent's psychological well-being after a child's intensive care unit discharge." *Nurs Crit Care* 2019, 24(3): 153-161.
14. Colville GA and Gracey D. "Mothers' recollections of the Paediatric Intensive Care Unit: Associations with psychopathology and views on follow up." *Intensive and Critical Care Nursing* 2006, 22(1): 49-55.
15. Caspani G, Corbet Burcher G, Garralda ME et al. "Inflammation and psychopathology in children following PICU admission: an exploratory study." *Evidence Based Mental Health* 2018, 21(4): 139.
16. Department of Health. Comprehensive Critical Care: a review of adult critical care services, 2000. Available from:
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4006585
17. Rattray J and Crocker C. The intensive care follow-up clinic: current provision and future direction? *Nursing in Critical Care* 2007, 12 (1) 1-3
18. Samuelson KA and Corrigan I. "A nurse-led intensive care after-care programme - development, experiences and preliminary evaluation." *Nurs Crit Care* 2009, 14(5): 254-263.

19. Strahan E, McCormick J, Uprichard E, et al. "Immediate follow-up after ICU discharge: establishment of a service and initial experiences." *Nurs Crit Care* 2003, 8(2): 49-55.
20. Hopkins RO, Choong K, Zebuhr CA, et al: Transforming PICU culture to facilitate early rehabilitation. *J Pediatr Intensive Care* 2015, 4(04), pp 204-211
21. Kastner K, Pinto N, Msall ME et al: PICU Follow-Up: The Impact of Missed School in a Cohort of Children Following PICU Admission. *Crit Care Explor* 2019, 1(8), pp e0033
22. Andrews, B. and N. Pinto (2019). "Optimizing Discharge from Intensive Care and Follow-Up Strategies for Pediatric Patients." *The Journal of Pediatrics* 205: 8-9.
23. Kjer CKW, Estrup S, Poulsen LM, et al: Follow-up after intensive care treatment: a questionnaire survey of intensive care aftercare in Denmark. *Acta Anaesthesiol Scand* 2017, 61(8), pp 925-934
24. Pearson G, Shann F, Barry P, et al: Should paediatric intensive care be centralised? Trent versus Victoria. *The Lancet* 1997, 349(9060), pp 1213-1217
25. Department of Health: Paediatric intensive care: A framework for the future. Wetherby: Department of Health; 1997.
26. Roussak P: Centralisation of paediatric intensive care and a 24-hour retrieval service. *Br J Nurs* 2014, 23(1), pp 25-29
27. National Institute for Health and Care Excellence: Rehabilitation after critical illness in adults. Quality Standard [QS158]. London NICE; 2017.
28. Treble-Barna A, Beers SR, Houtrow AJ, et al: PICU-Based Rehabilitation and Outcomes Assessment: A Survey of Pediatric Critical Care Physicians. *Pediatr Crit Care Med* 2019, 20(6), pp e274-e282
29. Manning JC, Hemingway P, Redsell SA: Survived so what? Identifying priorities for research with children and families post-paediatric intensive care unit. *Nurs Crit Care* 2017, 23(2), pp 68-74
30. Prescott HC, Iwashyna TJ, Blackwood B, et al: Understanding and Enhancing Sepsis Survivorship. Priorities for Research and Practice. *Am J Respir Crit Care Med* 2019, 200(8), pp 972-981

265 **Table legend**

266 Table 1: Characteristic, content and perceptions of 'In-hospital PICU' follow-up

267 Table 2: Characteristic, content and perceptions of post-discharge follow-up

268

Table 1: Characteristic, content and perceptions of 'In-hospital PICU' follow-up	PICUs n (%)	
Policy, guideline or procedure on follow-up	10	
Yes	4	(40%)
No	5	(50%)
Don't know	1	(10%)
Eligibility criteria for follow-up*		
All - There is no specific criteria	5	
Dependent on Disease group or Therapeutic intervention(s): Long term ventilation n =1; Cardiac surgery n =1.	2	
Other: Screening for risk factors that may indicate need for follow-up n =1; nothing specific, just as required n=1; reviewed by our outreach service if requested by the ward n=1	3	
Standardised checklist for follow-up		
Yes	3	(30%)
No	6	(60%)
Don't know	1	(10%)
Follow-up team members*		
Doctor	5	
Nurse	4	
Specialist Nurse	4	
Family Liaison Nurse/Worker	4	
Physiotherapist	3	
Occupational Therapist	1	
Psychologist	3	
Pharmacist	1	
Dietitian	2	
Other: Clinical site practitioners n = 1; Social workers n = 1	2	
Mode of contact*		
Telephone call with the ward team	4	
Face-to-face discussion with ward staff	3	
Face-to-face patient consultation	8	
Other: Variable, dependent on patient need n = 2	2	
Time to contact		
The patient is not visited on the ward	1	(10%)
24-48 h	3	(30%)
>7 days	1	(10%)
Varies according to patient and family's needs	4	(40%)
Don't Know	1	(10%)
Information reviewed*		
Observation charts	7	
Blood work and results	4	
Drug chart/medications	5	
Fluid therapy plan	5	
Pain, sedation and withdrawal management	4	
Nursing plan	4	
Physiotherapy plan	1	
Other: Wound care n = 1; Individualised for each patient n = 2	3	
Care needs assessed*		
Tracheostomy care	4	
Respiratory care including CPAP and suction	4	
Nutrition	3	
Mobilization	2	
Medication weaning plan (sedation and withdrawal)	5	
Emotional health and wellbeing	2	
Parental/family psycho-social needs	4	
Medical care needs are not reviewed	1	

Other (Holistic assessment and escalation to other teams as required (2); varies depending on the patient (2))	4	
I believe early follow-up is important after a child's admission to PICU	22	
Agree	19	(86%)
Disagree	2	(9%)
Don't know	1	(5%)
Reasons for not offering follow-up*	12	
Patient's speciality ward team will address any follow up and follow-up issues/ patients' needs met by other services	6	
Do not perceive it is a need at the moment	2	
Not enough staff	9	
Too few financial resources	9	
There is resistance from wards	1	
Other: Problem with delayed discharges- follow-up is provided within PICU	1	

Please note: only options that participants selected are reported in this table.

*Possible to select more than one answer.

Table 2: Characteristic, content and perceptions of post-discharge follow-up		PICUs	
		n	(%)
Policy, guideline or procedure on follow-up		4	
No		4	(100%)
Eligibility criteria for follow-up*			
Dependent on Disease group or Therapeutic intervention(s) (Only offered to those when the child has died(1); Neuro-trauma, Receipt of ECMO, Long-term ventilation (1))		2	
Other (In those patients who have identified and ongoing issues in early follow-up (2))		2	
Standardised checklist for follow-up			
No		3	(75%)
Don't know		1	(25%)
Follow-up team members*			
Doctor		3	
Nurse		2	
Specialist Nurse		1	
Health care assistant		1	
Physiotherapist		1	
Psychologist		1	
Pharmacist		1	
Dietitian		1	
Other (Dependent on what interventions are required (1))		1	
Mode of contact*			
Telephone consultation with patient/family		2	
Rehabilitation clinic		1	
Home visit		1	
Other (On the PICU (1); Quiet room away from the PICU (1))		2	
Time to contact			
1-<3 months		2	(50%)
Varies according to patient and family's needs		2	(50%)
Care needs assessed*			
Dependent upon the patient		3	
General assessment of how the PICU survivor is doing		1	
Assessment of physical/functional status of PICU survivor		1	
Assessment of emotional/mental health status of PICU survivor		1	
Assessment of social status and functioning of PICU survivor		1	
Assessment of parent/legal guardian emotional/mental health status		1	
Assessment of sibling emotional status		1	
Assessment of sibling social status/functioning		1	
Other (Assessment of family needs (1))		1	
I believe late follow-up is important after a child's admission to PICU		22	
Agree		16	(72%)
Disagree		3	(14%)
Don't know		3	(14%)
Reasons for not offering follow-up*		18	
Benefits are unclear		5	
Patient's speciality ward team will address any follow up and follow-up issues/ patients' needs met by other services		10	
Not enough staff		5	
Too few financial resources		5	
Other (Wide geographic area (1); Crossover with other specialities (2); organised by ward/specialist nurse (1); follow-up service is being developed (1))		5	

Please note: only options that participants selected are reported in this table.

*Possible to select more than one answer.

UK PICU aftercare-survey

Welcome

Thank you for clicking on the link to this survey.

The purpose of this survey is to evaluate current provision of aftercare for children and their families that are discharged from the PICU. We are specifically interested in the role of the PICU multidisciplinary team (including Critical Care Outreach) in the delivery of aftercare.

The survey consists of questions relating to four areas: [1] Early aftercare (in hospital); [2] Late aftercare (after hospital); [3] Future developments; [4] About your PICU/Hospital.

The survey takes approximately 10 minutes to complete.

We require only 1 response per PICU.

To submit your responses you **must click 'Finish'**

Your responses will be anonymised and will be used to inform the development of future research projects focused at supporting children and their families following PICU. This survey is endorsed by PICS-SG and has been registered as a service evaluation with Nottingham University Hospitals NHS Trust [Project Number:17-207c].

The findings will be disseminated to PICS-SG and in a peer-reviewed publication.

Thank you in advance for your time.

If you have any questions about this survey or the project please contact Dr Joseph Manning; email - joseph.manning@nottingham.ac.uk

We would like to acknowledge the following: Cilia Kjer (Department of Anaesthesia, Zealand University Hospital, Denmark) for permission to use the follow-up after intensive care treatment survey and undertaking the initial translation of the survey from Danish to English; Dr Lyvonne Tume and Gillian Colville with the UK validation of the survey.

This survey should not to be used without permission of the study team: Dr Joseph Manning, Dr Barney Scholefield and Professor Jos Latour.

Manning et al ., (2020)

Early aftercare (in hospital)

Early aftercare (in hospital) is defined as,

- Any activity initiated and delivered by the paediatric intensive care unit (PICU) in the period after transfer to the ward, but **before** discharge from the hospital.
- It is often associated with follow-up, outreach, and rehabilitation.
- It **does not include** the handover of the patient from the intensive care unit to the ward.

1. Does your PICU offer early aftercare for patients transferred to the ward? *

Required

- ☐ Yes
- ☐ No
- ☐ Don't know

Early aftercare (in hospital)

2. Please describe what early aftercare involves? *Optional*

Early aftercare (in hospital)

3. Does your hospital have a policy, guideline or procedure for early aftercare to PICU patients? * *Required*

- ☐ Yes
- ☐ No
- ☐ Don't know

4. Which PICU patients are offered early aftercare? * *Required*

[+ More info](#)

- ☐ All. There is no specific criteria
- ☐ They are selected depending on the length of stay in the intensive care unit
- ☐ They are selected depending on how long the patient is mechanically ventilated
- ☐ They are selected on disease group or therapeutic intervention
- ☐ Other

4.a. If you selected Other, please specify:

Early aftercare (in hospital)

5. Please specify the length of stay of patients that receive early aftercare

- ☐ <24 hours
- ☐ 24 hours - 48 hours
- ☐ 48 hours - 7 days
- ☐ > 7 days
- ☐ Other

5.a. If you selected Other, please specify:

Early aftercare (in hospital)

6. If your referral is based on the length of ventilation, what length of ventilation would you refer for aftercare?

- ☐ <24 hours
- ☐ 24 hours - <48 hours
- ☐ 48 hours - 7 days
- ☐ > 7 days
- ☐ Other

6.a. If you selected Other, please specify:

Early aftercare (in hospital)

7. What PICU patient groups are offered early aftercare? (tick all that apply)

- ☐ Cardiac arrest (requiring CPR)
- ☐ Neuro-trauma
- ☐ Receipt of ECMO
- ☐ Sepsis
- ☐ Long-term ventilation
- ☐ Other

7.a. If you selected Other, please specify:

Early aftercare (in hospital)

8. Which professionals provide early aftercare? (tick all that apply) * *Required*

Please select at least 1 answer(s).

- ☐ Doctor
- ☐ Nurse
- ☐ Specialist Nurse
- ☐ Family Liaison Nurse/Worker
- ☐ Health care assistant
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Psychologist
- ☐ Pharmacist
- ☐ Dietitian
- ☐ Other

8.a. If you selected Other, please specify:

9. What forms of contact does your early aftercare include? (tick all that apply)

- ☐ Call to the ward team
- ☐ Face-to-face discussion with ward staff
- ☐ Face to face patient review
- ☐ Other

9.a. If you selected Other, please specify:

10. Does your hospital have a standardised checklist for what the early aftercare contact should contain? * *Required*

- ☐ Yes
- ☐ No
- ☐ Don't know

11. What information is reviewed with the ward team as part of early aftercare? (tick all that apply)

- ☐ Observation charts
- ☐ Blood work and results
- ☐ Drug chart/ medications
- ☐ Fluid therapy plan
- ☐ Pain, sedation and withdrawal management
- ☐ Nursing plan
- ☐ Physiotherapy plan
- ☐ Occupational Therapy Plan, including aids
- ☐ Other

11.a. If you selected Other, please specify:

12. What aspects of patient medical care needs are assessed on the ward as part of

early aftercare?

- ☐ Tracheostomy care
- ☐ Respiratory care incl. CPAP and suction
- ☐ Nutrition
- ☐ Vascular access
- ☐ Mobilization
- ☐ Medication weaning plan (sedation and withdrawal)
- ☐ Emotional health and wellbeing
- ☐ Parental/family psycho-social needs
- ☐ Medical care needs are not reviewed
- ☐ Other

12.a. If you selected Other, please specify:

13. What information is communicated to the patient and their family? (tick all that apply)

- ☐ Prospective treatment plan
- ☐ Prospective care needs
- ☐ Transition from the PICU to the ward
- ☐ Patient's stay in the PICU
- ☐ Other

13.a. If you selected Other, please specify:

Early aftercare (in hospital)

14. If the patient is followed up, how long after transferring from the PICU does this usually occur?

- ☐ The patient is not visited on the ward
- ☐ <24 hours
- ☐ 24 hours - 48 hours
- ☐ 48 hours - 7 days
- ☐ > 7 days
- ☐ Other
- ☐ Don't know

14.a. If you selected Other, please specify:

Early aftercare (in hospital)

15. Please identify if there are any reasons why your PICU does not offer early aftercare? (tick all that apply)

- ☐ The benefits of early aftercare are unclear
- ☐ The patient's speciality ward team will address any follow up and aftercare issues
- ☐ Early aftercare is not relevant to the patients that leave the PICU
- ☐ We don't see it is a need at the moment
- ☐ Not enough staff
- ☐ Too few financial resources
- ☐ There is resistance from wards
- ☐ Other
- ☐ Don't know

15.a. If you selected Other, please specify:

Late aftercare (after hospital discharge)

This part of the questionnaire is about late aftercare. Late PICU-aftercare is defined as any activity initiated by the PICU in the period after discharge from the hospital. It is often mentioned synonymously with follow-up and rehabilitation.

16. Does your PICU offer late aftercare? * *Required*

- ☐ Yes
- ☐ No
- ☐ Don't know

Late aftercare (after hospital discharge)

17. Please describe what this involves? *Optional*

Late aftercare (after hospital discharge)

18. Does your PICU have a policy, guideline or procedure for late aftercare? *
Required

- ☐ Yes
- ☐ No
- ☐ Don't know

19. How are PICU patients selected for late aftercare? * *Required*

- ☐ Offered to all
- ☐ They are selected depending on the length of stay in the intensive care unit
- ☐ They are selected depending on how long the patient is mechanically ventilated
- ☐ They are selected on disease group or therapeutic intervention
- ☐ In those patients in who have identified and ongoing issues in early aftercare
- ☐ Other

19.a. If you selected Other, please specify:

Late aftercare (after hospital discharge)

20. Please specify the length of PICU stay of patients that are offered late aftercare

- ☐ <24 hours
- ☐ 24 hours - 48 hours
- ☐ 48 hours - 7 days
- ☐ > 7 days
- ☐ Other

20.a. If you selected Other, please specify:

Late aftercare (after hospital discharge)

21. Please specify the time in receipt of invasive mechanical ventilation for the patient to be offered late aftercare

- ☐ <24 hours
- ☐ 24 hours - 48 hours
- ☐ 48 hours - 7 days
- ☐ > 7 days
- ☐ Other

21.a. If you selected Other, please specify:

Late aftercare (after hospital discharge)

22. What PICU patient groups are offered late aftercare? (tick all that apply)

- ☐ Cardiac arrest (requiring CPR)
- ☐ Neuro-trauma
- ☐ Receipt of ECMO
- ☐ Sepsis
- ☐ Long-term ventilation
- ☐ Bereaved
- ☐ Other

22.a. If you selected Other, please specify:

Late aftercare (after hospital discharge)

23. Which professionals provide late aftercare for patients discharged from PICU? (tick all that apply)

- ☐ Doctor
- ☐ Nurse
- ☐ Nurse specialist
- ☐ Family Liaison Nurse
- ☐ Health care assistant
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Psychologist
- ☐ Pharmacist
- ☐ Dietitian
- ☐ Other

23.a. If you selected Other, please specify:

24. How does your PICU contact the patients for late aftercare? (tick all that apply)

- ☐ By phone
- ☐ Letter
- ☐ E-mail
- ☐ SMS (text message)
- ☐ Other

24.a. If you selected Other, please specify:

25. How long after PICU discharge would patients normally receive late aftercare?

- ☐ <1 month
- ☐ 1 - <3 months
- ☐ 3 months - 6 months
- ☐ 6 months - 12 months
- ☐ > 12 months
- ☐ It varies according to the patient/families needs
- ☐ Don't know

26. What form does your late aftercare involve?

- ☐ Telephone consultation
- ☐ The patient/family meets in the PICU
- ☐ The patient will meet in a PICU-rehabilitation clinic / outpatient clinic
- ☐ Home visits
- ☐ Skype/Tele-consultation

☐ Other

26.a. If you selected Other, please specify:

27. Is there a standardised checklist for what the late aftercare contact should contain?

- ☐ Yes
- ☐ No
- ☐ Don't know

Late aftercare (after hospital discharge)

28. What does late aftercare involve? (tick all that apply)

- ☐ A general assessment of how the PICU survivor is doing?
- ☐ Assessment of physical/functional status of PICU survivor
- ☐ Assessment of cognitive status of PICU survivor
- ☐ Assessment of emotional/mental health status of PICU survivor
- ☐ Assessment of social status and functioning of PICU survivor
- ☐ Assessment of parent/legal guardian emotional/mental health status
- ☐ Assessment of parent/legal guardian social status
- ☐ Assessment of sibling emotional status
- ☐ Assessment of sibling social status/functioning
- ☐ Other

28.a. If you selected Other, please specify:

Late aftercare (after hospital discharge)

29. Please select any reasons why your PICU does not offer late aftercare? (tick all that apply)

- ☐ Patients needs met by other services
- ☐ Unclear of the benefits of providing late aftercare
- ☐ Too many cancellations / patients do not respond to requests
- ☐ Late aftercare is not relevant to the patient
- ☐ Not enough staff
- ☐ Too few resources
- ☐ Other

29.a. If you selected Other, please specify:

Future developments

This part is about the future development of early and late aftercare

30. Please rate the following statements

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

	Totally agree	Partially agree	Partially disagree	Totally disagree	Do not know
I believe early aftercare is important after a child's admission to PICU	☐	☐	☐	☐	☐
I believe late aftercare is important after a child's admission to PICU	☐	☐	☐	☐	☐

31. What plans does your PICU have (if any) for the provision of **early aftercare a year from now**?

- ☐ More resources
- ☐ Same amount of resources
- ☐ Fewer resources
- ☐ No plans for any change
- ☐ Other
- ☐ Don't know

32. What plans does your PICU have (if any) for the provision of **late aftercare a year from now**?

- ☐ More resources
- ☐ Same amount of resources
- ☐ Fewer resources
- ☐ No plans for any change
- ☐ Other
- ☐ Don't know

About your PICU/Hospital

This is the last part of the questionnaire and includes questions about your PICU and hospital.

33. Please select your PICU from the list. * *Required*

34. Please select the number (range) of **paediatric beds in your hospital**

- ☐ <50
- ☐ 51-100
- ☐ 101-150
- ☐ 151-200
- ☐ 201-250
- ☐ >251

35. If you have any additional comments that you feel are useful to this evaluation please write them in the box below:

36. Can we contact you if we have any additional questions based on this survey? * *Required*

☐ Yes

☐ No

Contact details

37. Please provide your name:

38. Please provide your email address:

Please enter a valid email address.

39. Please provide your contact telephone number:

Thank you

Thank you for taking the time to complete this survey.

Please click the '**Finish**' button below to submit your responses.

Acknowledgements

This survey was adapted from the 'Follow-up after intensive care treatment survey' developed by C.K.W. Kjer , S. Estrup , L. M. Poulsen and O. Mathiesen from the Department of Anaesthesiology, Zealand University Hospital, Køge, Denmark. We would like to thank Cilia Kjer for translating the survey into English language and granting permission for us to adapt it for use in this project.

We would also like to thank the group of PICU experts that assessed the survey for face and content validity for use in a UK context.

This project is being funded through a 2017 Clinical Gold Scholarship from Health Education England - East Midlands awarded to Dr Joseph Manning.

End

Key for selection options

33 - Please select your PICU from the list.

Addenbrooke's Hospital, Cambridge University Hospitals NHS Foundation Trust
Birmingham Children's Hospital, Birmingham Children's Hospital NHS Trust
Bristol Royal Hospital for Children, University Hospitals Bristol NHS Foundation Trust
Evelina London Children's Hospital, Guy's & St. Thomas' NHS Foundation Trust
Great Ormond Street Hospital for Children, Great Ormond Street Hospital for Children NHS Trust
Great North Children's Hospital & Newcastle Freeman Hospital, Newcastle Upon Tyne Hospitals NHS Foundation Trust
Hull Royal Infirmary, Hull & East Yorkshire Hospitals NHS Trust
King's College Hospital, King's College Hospital NHS Trust
Leeds General Infirmary, Leeds Teaching Hospitals NHS Trust
Leicester Glenfield Hospital, University Hospitals of Leicester NHS Trust
Leicester Royal Infirmary, University Hospitals of Leicester NHS Trust
Liverpool Alder Hey Children's Hospital, Liverpool Alder Hey Children's NHS Foundation Trust
Nottingham Childrens Hospital, Nottingham University Hospitals NHS Trust
Royal Belfast Hospital for Sick Children, Belfast Health and Social Care Trust
Royal Hospital for Sick Children (Edinburgh), NHS Lothian – University Hospitals Division
Royal Hospital for Sick Children (Yorkhill), NHS Greater Glasgow and Clyde
Royal Manchester Children's Hospital, Central Manchester University Hospitals NHS Foundation Trust
Royal Brompton Hospital, Royal Brompton & Harefield NHS Foundation Trust
Sheffield Children's Hospital, Sheffield Children's NHS Foundation Trust
Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust
St. George's Hospital, St. George's University Hospitals NHS Foundation Trust
St. Mary's Hospital, Imperial College Healthcare NHS Trust
Temple Street, Dublin & Our Lady's Children's Hospital, HSE (Health Services Executive), Children's University Hospital
The Harley Street Clinic & The Portland Hospital for Women and Children, HCA Healthcare

The James Cook University Hospital, South Tees Hospitals NHS Foundation Trust
The John Radcliffe Hospital, Oxford University Hospitals NHS Trust
The Royal London Hospital, Barts and the London NHS Trust
University Hospital of North Staffordshire, University Hospital of North Staffordshire
NHS Trust
University Hospital of Wales, Cardiff & Vale NHS Trust