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

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## **Conflict of Interest statement:**

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

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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.

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## **Abstract**

### **Objective**

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

### **Design**

Descriptive self-reported, web-based survey design.

'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.

### **Setting**

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

### **Participants**

Pediatric Intensive Care medical directors or delegated individual.

### **Measurements and main results**

Data were collected between September 2017-January 2018 with a response rate of 79% (n=22/28). Twelve units provided either in-hospital and/or post-discharge PICU follow-up. Ten (45%) PICUs reported providing in-hospital follow-up, with half (n=5) using an eligibility criteria for in-hospital follow-up which related to disease groups. The most frequently reported form of in-hospital PICU follow-up consisted of face-to-face patient consultation (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.

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

## Introduction

Globally the numbers of children that survive critical illness are at an all-time high [1].

However, evidence suggests that critical illness can cause iatrogenic harm due to treatment and environmental factors [2, 3]. As such, for some children and their families, transitioning out of the Paediatric Intensive Care Unit (PICU) to longer-term survival may result in physical deconditioning, cognitive impairment, as well as emotional and social adversities [4-11].

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

Despite national guidance for adults that experience critical illness and require admission to intensive care, which asserts that follow-up should be provided as a way to meet patients' psychological needs and improve the quality of their recovery [16], similar guidance within paediatrics is lacking. In addition to a lack of guidance, barriers to the provision of intensive care follow-up are reported to include deficits in the evidence to demonstrate its effectiveness and the subsequent allocation of adequate resources [17]. However, other authors have described that the provision of intensive care follow-up services requires only 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).

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

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

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

### **Discussion**

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

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

### **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.

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Table 1: Characteristic, content and perceptions of 'In-hospital PICU' follow-up	PICUs	
	n	(%)
<b>Policy, guideline or procedure on follow-up</b>	<b>10</b>	
Yes	4	(40%)
No	5	(50%)
Don't know	1	(10%)
<b>Eligibility criteria for follow-up*</b>		
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	
<b>Standardised checklist for follow-up</b>		
Yes	3	(30%)
No	6	(60%)
Don't know	1	(10%)
<b>Follow-up team members*</b>		
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	
<b>Mode of contact*</b>		
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	
<b>Time to contact</b>		
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%)
<b>Information reviewed*</b>		
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	
<b>Care needs assessed*</b>		
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	
<b>I believe early follow-up is important after a child's admission to PICU</b>	<b>22</b>	
Agree	19	(86%)
Disagree	2	(9%)
Don't know	1	(5%)
<b>Reasons for not offering follow-up*</b>	<b>12</b>	
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	(%)
<b>Policy, guideline or procedure on follow-up</b>	<b>4</b>	
No	4	(100%)
<b>Eligibility criteria for follow-up*</b>		
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	
<b>Standardised checklist for follow-up</b>		
No	3	(75%)
Don't know	1	(25%)
<b>Follow-up team members*</b>		
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	
<b>Mode of contact*</b>		
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	
<b>Time to contact</b>		
1-<3 months	2	(50%)
Varies according to patient and family's needs	2	(50%)
<b>Care needs assessed*</b>		
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	
<b>I believe late follow-up is important after a child's admission to PICU</b>	<b>22</b>	
Agree	16	(72%)
Disagree	3	(14%)
Don't know	3	(14%)
<b>Reasons for not offering follow-up*</b>	<b>18</b>	
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.