Paediatric Intensive Care Audit Network
Annual Report 2019

Summary Report
Data collection period
January 2016–December 2018
Organisation key

A  Addenbrooke’s Hospital, Cambridge
C  Noah’s Ark Children’s Hospital for Wales, Cardiff
D  Royal Manchester Children’s Hospital
E1 Great Ormond Street Hospital, London (PICU/NICU)
E2 Great Ormond Street Hospital, London (CICU)
F  Evelina London Children’s Hospital
H  King’s College Hospital, London
I  Leeds General Infirmary
K2 Freeman Hospital, Newcastle upon Tyne
K3 Great North Children’s Hospital, Newcastle upon Tyne
L  Royal Stoke University Hospital
M  Nottingham Children’s Hospital, Queens Medical Centre, Nottingham
N  John Radcliffe Hospital, Oxford
O  Royal Brompton Hospital, London
P  Alder Hey Children’s Hospital, Liverpool
Q  Sheffield Children’s Hospital
R  Southampton Children’s Hospital
S  James Cook University Hospital, Middlesbrough
T  St George’s Hospital, London
U  St Mary’s Hospital, London
V  Birmingham Children’s Hospital
W  Bristol Royal Hospital for Children
X1 Glenfield Hospital, Leicester
X2 Leicester Royal Infirmary
Y  Royal Hospital for Sick Children, Edinburgh
Z  The Royal London Hospital
ZA Royal Hospital for Children, Glasgow
ZB Royal Belfast Hospital for Sick Children
ZC Children’s Health Ireland at Crumlin, Dublin (formerly Our Lady’s Children’s Hospital, Crumlin)
ZD Children’s Health Ireland at Temple Street, Dublin (formerly Temple Street Children’s University Hospital)
ZE Harley Street Clinic, London
ZF The Portland Hospital, London
T001 Children’s Acute Transport Service (CATS)
T002 Embrace: Yorkshire & Humber Infant & Children’s Transport Service
T003 North West and North Wales Paediatric Transport Service (NWTS)
T004 South Thames Retrieval Service (STRS)
T005 KIDS Intensive Care and Decision Support
T008 Southampton Oxford Retrieval Team (SORT)
T010 Northern Ireland Specialist Transport and Retrieval (NISTAR) Paediatric
T020 Scotland Specialist Transport and Retrieval (ScotSTAR)
T022 Irish Paediatric Acute Transport Service (IPATS)
T024 Wales and West Acute Transport for Children (WATCH)
T026 North East Children’s Transport and Retrieval Service (NECTAR)
T027 Children’s Medical Emergency Transport Service (CoMET)
T028 Heartlink ECMO Children’s Service

Published in the UK by the Paediatric Intensive Care Audit Network (PICANet). This work is copyright. Apart from any use as permitted under the Copyright, Designs and Patents Act 1988, no part may be reproduced by any process without permission from PICANet.

Requests and enquiries concerning reproduction rights should be directed to PICANet at:
PICANet, School of Medicine, University of Leeds, Clarendon Way, Leeds, LS2 9JT
Telephone 0113 343 8125  Email picanet@leeds.ac.uk

In all cases, PICANet must be acknowledged as the source when reproducing or quoting any part of this publication. Please use the following format when citing this report: Paediatric Intensive Care Audit Network Annual Report 2019 (published December 2019): Universities of Leeds and Leicester

For this report content is © 2019 The Healthcare Quality Improvement Partnership.

The ISBN number for this publication is 978-0-85316-359-6
## Contents

Acknowledgements ................................................................................................................ 5  
Introduction ............................................................................................................................ 7  
Key findings ........................................................................................................................... 8  
Recommendations ............................................................................................................... 11  
How we present our results ................................................................................................. 13  
Headline figures: Admission numbers and bed days ............................................................ 14  
Headline figures: Admission rates by country of residence ................................................ 18  
Headline figures: Death in PICU .......................................................................................... 22  
Headline figures: Unplanned extubation ............................................................................. 24  
Headline figures: Referral for transport ............................................................................. 28  
Headline figures: Bed occupancy during ‘normal hours’ and ‘out of hours’ ......................... 30  
Metric 1: Case ascertainment and timeliness of data submission ........................................... 32  
Metric 2: Retrieval mobilisation times ............................................................................... 36  
Metric 3: Number of nurses providing clinical care per bed ................................................. 38  
Metric 4: Emergency readmissions within 48 hours ............................................................. 40  
Metric 5: Mortality in PICU ................................................................................................. 44  
Variation in levels of care provision in designated PICUs from 2010 to 2018 ....................... 47  
References .......................................................................................................................... 59  
Additional information ....................................................................................................... 61

For the Tables, Figures and Appendices relating to this report, please visit the PICANet website [www.picanet.org.uk](http://www.picanet.org.uk).
Acknowledgements

This work uses data provided by patients and collected by the organisation providing paediatric intensive care and transport services as part of their care and support.

The continued success of this international clinical audit is due to the hard work and commitment of those within the paediatric intensive care community. We are very grateful to all the audit clerks, secretaries, nurses and doctors who support and contribute to the Paediatric Intensive Care Audit Network (PICANet) from their own paediatric intensive care units (PICUs) and centralised transport services (CTS).

PICANet was established in collaboration with the Paediatric Intensive Care Society (PICS) and their active support continues to be a key component of our successful progress. The PICANet Steering Group (SG) has patient, academic, clinical, government and NHS members all of whom are thanked for their continuing assistance and advice. Members of the Clinical Advisory Group (CAG) provide a formal interface between PICANet and the clinical care teams and their valuable support and contribution is gratefully acknowledged.

The PICANet Audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), the Welsh Health Specialised Services, NHS Lothian/National Services Division NHS Scotland, the Royal Belfast Hospital for Sick Children, The National Office of Clinical Audit (NOCA) for the Republic of Ireland and HCA Healthcare UK. HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the NCAPOP, comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.

http://www.hqip.org.uk/national-programmes
Introduction

This is the sixteenth annual PICANet clinical audit report summarising paediatric critical care that took place in the United Kingdom (UK) and Republic of Ireland (ROI) between 2016 and 2018. PICANet continues to provide key information to monitor the quality of care and clinical outcomes in relation to agreed standards, and inform national policy in paediatric critical care.

This report provides data on five key metrics for Paediatric Intensive Care services: case ascertainment, retrieval mobilisation times, number of qualified nurses per bed, emergency readmissions within 48 hours and mortality in PICU. Although mortality remains the only metric for which outlier analysis is performed, we continue to support units in improving the quality of reporting of unplanned extubation events by providing regular feedback, with the ambition to incorporate this variable into outlier analysis in the near future. We also plan to assess whether unit volume and occupancy levels influence the risk of an emergency readmission to PICU to help reduce variation between providers for this metric.

This year we provide a chapter on the levels of care provision in the current designated PICUs across the United Kingdom and Republic of Ireland. This chapter builds on the analysis used to inform the NHS England Paediatric Critical Care and Specialised Surgery in Children Review, expanded to include the whole of the UK and ROI showing the current variation between level of care provision in PICUs. This complements sections on the five quality measures alongside core data on activity, mortality, specialist retrievals and transports, staffing and occupancy. Information is summarised by provider so that between-unit performance can be assessed. National and international comparative analyses are also available through individual country-level data as well as the whole of the UK and ROI.

We strongly encourage readers to access the full set of tables and figures available alongside this report which provide a more comprehensive assessment of PICU admissions, referrals and transport activity over the last three years. These are available in electronic form and individual tables can be downloaded in an Excel file format from www.picanet.org.uk.

PICANet is ideally placed to continue to monitor standards of care across PIC units and implement recommendations from the recent review in developing an extended dataset and series of metrics for level 2 critical care to assess demand and variation in performance. This work from England can be used to inform future reviews in the other countries covered by PICANet.

Professor Liz Draper
Dr Richard Feltbower,
Principal Investigators
Key findings

- There were around 20,000 annual admissions to paediatric intensive care during 2016–2018 throughout the UK and Republic of Ireland. There was a slight fall in the number of admissions in English NHS units and in Wales in 2017 but this was not sustained into 2018.

- Units across the UK and ROI delivered around 140,000 bed days per year between 2016–2018 with a small reduction seen in 2017 driven by slight falls in English NHS units, Wales and the Republic of Ireland. Bed day frequency rose again in 2018 to 142,207 in line with the increase in admissions.

- Paediatric intensive care admission rates showed clear variation by country, with Northern Ireland comprising the highest rates of 174 admissions per 100,000 children. This contrasted with relatively lower admission rates of 135 per 100,000 in the Republic of Ireland. A much greater degree of variation was seen within countries, particularly in the Republic of Ireland and England.

- The risk of death whilst receiving care on PICUs remained low, with 96.5% of admissions over the 2016–2018 period discharged alive. Deaths on PICUs account for around 15% of all UK childhood fatalities in the population.

- Unplanned extubation rates ranged from 4–5 per 1,000 days of invasive ventilation in 2017 and 2018. However, this masked considerable between-unit variation in reported numbers of unplanned extubations.

- Over the period 2016 to 2018 specialist PIC transport services accepted 16,666 (92.1%) of referrals for urgent transfer to PIC. Of the 1,428 that were refused, two fifths were refused because there was no PIC team available.

- Reported rates of bed occupancy remain high in PICUs. During the PICANet staffing census week intensive care bed occupancy rates were over 80% in England (NHS), Northern Ireland and the Republic of Ireland and 96% in Scotland during ‘normal hours’. High dependency bed occupancy ‘in normal hours’ was reported at 100% or more in England (NHS), Wales, and the Republic of Ireland. ‘Out of hours’ bed occupancy was similarly high with reported rates of 100% Intensive Care (IC) bed occupancy for Wales and the Republic of Ireland and over 80% for Scotland and England (NHS). For high dependency (HD) care ‘out of hours’ bed occupancy was reported as over 100% for England. Lower rates were reported for the other devolved nations and the Republic of Ireland.

- At least 97% of admissions reported to PICANet from 14 PICUs in 2018 were confirmed after a validation exercise was undertaken, with eight units reporting 100% of cases.

- 83% of units across the UK and Republic of Ireland (excluding Northern Ireland) provided complete and timely admissions’ data to PICANet within three months of discharge. However, there were two units which completed fewer than 50% of their admission records within this timescale.

- Of the 4,224 journeys carried out for children requiring urgent transport to a PICU, just under three fifths (58.9%) were started within 30 minutes and three quarters (76.7%) started within one hour of the decision being made. Just over 1 in 20 journeys (5.9%) started more than three hours after this decision.
▪ One quarter of PICUs (24%) met the PICS standard for nursing staff of 7.01 WTEs (whole time equivalents) when all staff providing clinical care (including non-registered health care staff: Bands 2-4) are included. If recorded vacancies were filled to unit nurse establishment figures two fifths of PICUs (39%) would meet this standard. However, as in previous years, the annual PICANet census shows that units ensure their staffing levels are appropriate for the number of children on the unit and their care requirements.

▪ Emergency readmission rates within 48 hours of discharge remained steady at around 1.7% throughout the 2016–2018 period. However, rates varied substantially between units.

▪ No PICUs demonstrated any outlying performance with respect to their mortality rates between 2016 and 2018.

▪ There is significant variation in the level of care provision between PICUs across the UK and ROI. Whilst the amount of activity has increased over the period 2010 to 2018 across all levels of care the proportion of each level of care delivered by the different types of PICU has changed. In 2016 to 2018, PICUs delivering extracorporeal membrane oxygenation (ECMO) had at least 50% of admissions requiring HRG levels of at least Intensive Care Basic Enhanced whilst less than 10% of their admissions only required basic critical care or below. In contrast for PICUs with designated intensive care beds alone the proportion of admissions requiring at least Intensive Care Basic Enhanced was less than 25% with over 20% of their admissions requiring basic critical care or below. For PICUs with designated high dependency beds the proportion of admissions requiring at least Intensive Care Basic Enhanced was around 15% with a further 30% of their admissions requiring basic critical care or below.
Recommendations

1. PICUs should work closely with commissioners to monitor bed occupancy levels in PICU to ensure adequate provision for the appropriate level of care during times of increased demand.

2. PICUs and PIC Centralised Transport Services should ensure that they submit complete and timely data to PICANet within three months of discharge or the time of the event in order to comply with the PICS standards.

3. PIC Centralised Transport Service teams should review their retrieval mobilisations times to understand the reasons for delays in cases where the 30 minute NHS England target is not achieved.

4. Nurse managers should investigate the use of non-registered health care staff to support qualified nurses in delivering clinical care, learning from units where this has already been established to facilitate appropriate staffing levels.

5. PIC clinicians should work with PICANet to identify and investigate the reasons for the variation in emergency readmission rates within 48 hours of discharge.

6. Variation in activity and levels of care provision in PICUs should be used by commissioners and clinical leads to inform the development of the new Operational Delivery Networks in England and future critical care provision across England, the devolved nations of the United Kingdom and the Republic of Ireland.

7. PICUs should ensure that the data collected to monitor unplanned extubation rates complies with the agreed PICANet definition. This will allow for the sharing of best practice between units to reduce the variation in unplanned extubation rates.
How we present our results

Results are presented in tables, figures and as maps. In general, data are presented for children aged 0–15 years, however data are also presented in separate tables for patients who are 16 years and older and treated on PICU. Each specific measure of interest is explained in the results and metrics sections of this report under the heading “What are we measuring?”

We look at a wide range of measures including the number of admissions, how many days patients are in PICU, the types of treatments patients receive and clinical outcomes such as death. We present data according to age, sex, country of admission, treating PICU as well as country of residence and where the child is living.

Rates

We present certain information in the form of rates, enabling comparisons to be made between countries even though the population size in each country is different. Rates are usually presented as the number per 1,000 or per 100,000 of the relevant population.

When we want to compare two rates we divide one rate by the other, to get a relative rate. For example, if we wanted to compare the admission rate in Scotland to that in England then we would divide the Scottish admission rate by the English admission rate. If the two rates were the same then the relative rate would be one. If the Scottish rate was higher than the English rate then the relative rate would be greater than one. If the Scottish rate was lower than the English rate then the relative rate would be less than one. This measure allows us to talk about the Scottish rate in comparison (or relative) to the English rate.

Deaths

We measure how poorly children were at the point when they were admitted to PICU using the Paediatric Index of Mortality 3 (PIM3). This takes into account many factors such as whether the child was admitted as an emergency and whether they needed help breathing to estimate how likely each child is of dying.

When comparing deaths in PICU, we calculate the risk-adjusted standardised mortality ratio (SMR). This compares the number of deaths that have happened in a PICU and how many deaths we expected to happen given how poorly children were when they were admitted to PICU. We also use ‘funnel plots’ to compare individual PICUs in terms of mortality which is a way of displaying and comparing the risk-adjusted SMR on the same graph. These plots tell us what range of values we might expect to see for the SMR in each PICU, given that we expect a certain amount of variation as these calculations are based on a very small number of deaths. Further details on funnel plots and how to interpret them are provided in the ‘Metric 5: Mortality in PICU’ section.
Headline figures: Admission numbers and bed days

What are we measuring?

Table 1 and Figure 1 below summarise the number of admissions to paediatric intensive care units in the UK and Republic of Ireland between 2016 and 2018 among children aged under 16 years. Table 2 and Figure 2 summarise the number of bed days of paediatric intensive care that were delivered during this period.

What did we find?

There were approximately 20,000 admissions to PICUs every year between 2016 and 2018 across the UK and Republic of Ireland. Following a small decrease in 2017 the number of admissions increased in 2018, driven by trends in England (NHS units) and to a lesser extent in Wales. The number of bed days ranged from around 140,000 to 145,000. There was a similar, modest increase in the number of bed days delivered in 2018 following a small reduction in 2017, driven by trends in England (NHS units), Wales and the ROI.

Table 1: Number of admissions by country of PICU and year

<table>
<thead>
<tr>
<th>Country of admission</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>England (NHS)</td>
<td>15,958</td>
<td>15,474</td>
<td>16,009</td>
</tr>
<tr>
<td>England (non-NHS)</td>
<td>336</td>
<td>504</td>
<td>342</td>
</tr>
<tr>
<td>Wales</td>
<td>530</td>
<td>493</td>
<td>510</td>
</tr>
<tr>
<td>Scotland</td>
<td>1,486</td>
<td>1,393</td>
<td>1,353</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>557</td>
<td>522</td>
<td>501</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>1,401</td>
<td>1,463</td>
<td>1,428</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20,268</strong></td>
<td><strong>19,849</strong></td>
<td><strong>20,143</strong></td>
</tr>
</tbody>
</table>

N.B. This table does not include admissions where the child’s age is unknown.

Figure 1: Number of admissions to PICU by country of admission and year
Table 2: Number of bed days delivered by country of admission and year

<table>
<thead>
<tr>
<th>Country of admission</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>England (NHS)</td>
<td>113,450</td>
<td>110,026</td>
<td>113,756</td>
</tr>
<tr>
<td>England (non-NHS)</td>
<td>3,473</td>
<td>2,603</td>
<td>2,386</td>
</tr>
<tr>
<td>Wales</td>
<td>2,757</td>
<td>2,451</td>
<td>2,509</td>
</tr>
<tr>
<td>Scotland</td>
<td>11,020</td>
<td>10,768</td>
<td>10,321</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>3,480</td>
<td>3,695</td>
<td>3,282</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>10,319</td>
<td>9,607</td>
<td>9,953</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>144,499</strong></td>
<td><strong>139,150</strong></td>
<td><strong>142,207</strong></td>
</tr>
</tbody>
</table>

N.B. This table does not include admissions where the child’s age is unknown.

Figure 2: Number of bed days delivered by country of admission and year

What does this mean?

Paediatric intensive care services continue to experience high demand across the UK and Republic of Ireland; this is reflected in an average of over 50 new admission events per day. The small decrease in admissions and bed days seen in 2017 was not sustained into 2018. These apparent changes in trends from one year to the next illustrate the requirement to closely monitor PICU demand not only in terms of admission burden but equally for the number of bed days provided.
Further details

Definitions and methods

Every admission to a PICU in the UK and the Republic of Ireland is counted for each year, 2016–2018. If a child has been readmitted during that period this will be counted as a separate admission. A ‘bed day’ is counted if a child is in a PICU bed for a day or part of a day which occurs within the reporting period (i.e. between 1st January 2016 and 31st December 2018).

We have only provided figures for children less than 16 years old (the normal age limit for admission to PICU) and have excluded any admissions where the age at admission was unknown. All designated PICUs across the UK and ROI provide data to PICANet. This includes the two private providers of PIC based in England.

Why is this important?

The number of admissions and the number of bed days tell us how busy the PICUs are and helps the commissioners, who provide funding for paediatric intensive care, to work out how many staff and beds are required to meet the demand. This is important, as too few beds might mean that a child may not receive intensive care when they need it, or there may be a delay. Although it is unlikely, if the commissioners overestimate demand, it is possible that staff and beds would be under-utilised, which would be a waste of resources.

The data regarding PICU admissions and bed days delivered have been used by the recent Paediatric Critical Care Review for England.
Headline figures: Admission rates by country of residence

What are we measuring?

Annual rates of admissions to PICU between 2016 and 2018 are presented in Figure 3 below by country of residence, calculated per 100,000 children in the population. This identifies what proportion of the childhood population are treated by paediatric intensive care services in each country every year. Figure 4 shows admission rates for each clinical commissioning group, health board or county in the UK and Republic of Ireland for the same period. This identifies what proportion of the childhood population were treated by paediatric intensive care services in each health region every year.

What did we find?

PICU admission rates were highest in Northern Ireland, reaching 174 admissions for every 100,000 children, followed by Scotland (163), Wales (142), England (141), and the Republic of Ireland (135). For the UK and Republic of Ireland combined, admissions rates were 143 per 100,000 population per year.

Admission rates in Northern Ireland ranged between 105 and 155 per 100,000 depending on Health Board. The Republic of Ireland showed slightly more variation ranging between 71 and 168 per 100,000. England showed substantial variation with admission rates ranging from 66 to 453 per 100,000. In Scotland, less variation was seen with admission rates ranging from 94 to 220 per 100,000. Wales showed a similar level of variation to Scotland with rates between 92 and 218 per 100,000.

Figure 3: Rate of admissions per 100,000 childhood population 2016–2018

Prevalence for admission

- 135.6 - 140.0
- 140.0 - 160.0
- 160.0 - 175.5

Figure 4: Rate of admissions per 100,000 childhood population by healthcare area 2016–2018

Prevalence for admission

What does this mean?

There was substantial geographical variation in admissions rates to PICU, both between and especially within countries: this represents essential information required for the planning of local PIC services by the specialist commissioners for each healthcare area. Possible explanations for these findings could involve differences in admission policies between each country, the availability of specialised critical care and transport services at the time of admission, and distance to the nearest PICUs.

Further details

Definitions and methods

Admission numbers are firstly recorded and then how many admissions have occurred for every 100,000 children aged under 16 in each of the UK countries and the Republic of Ireland in 2016–2018: this is called the admission rate. We used national census data to find out the childhood population in each country. We repeated this method looking at healthcare areas in the UK and Republic of Ireland; again using national census data to find out the childhood population size in each area. Each country uses different names for these healthcare areas: England has Clinical Commissioning Groups; Scotland and Wales have Health Boards; Northern Ireland has Health and Social Care Trusts. Healthcare area population data were not available for the Republic of Ireland, therefore County was used instead to present these data.

Why is this important?

It is important for each country participating in PICANet to know the rate of admission to paediatric intensive care to allow them to plan services effectively. Describing admission rates at a more granular healthcare level helps to identify areas within countries with higher and lower admission rates which could be important for service planning. The variation in admission rates could also be investigated to understand if these are real geographical differences (e.g. proximity to PICU, level of urbanicity) or explained by differences in clinical practise or commissioning in the populations for each region.
Headline figures: Death in PICU

What are we measuring?

All deaths that occur after admission but prior to discharge from PICU are recorded and reported here for children under 16 who were admitted between 2016 and 2018. Deaths are presented in two ways: firstly, based on the country of admission (i.e. PICU location) and secondly based on the patient’s recorded country of residence.

What did we find?

Table 3 summarises the number of deaths in PICU by country of admission and year. The percentages were calculated for each country based on the total number of admissions for that year. There was a total of 2,106 deaths over the three year period, equivalent to 965 children out of every 1,000 being discharged alive. Due to small numbers, data for non-NHS and NHS organisations in England are presented combined.

Table 4 shows the proportion of deaths in PICU, compared to all childhood deaths in the UK and Republic of Ireland, based on the country of residence. We also present the total number of deaths in the population in brackets. For children resident in the UK, PICU deaths accounted for between 15–17% of the total number of children’s deaths. For children resident in the Republic of Ireland, PICU deaths accounted for between 19–23% of the total number of children’s deaths.

Table 3: Proportion of deaths in PICU of all PICU admissions, by country of admission and year

<table>
<thead>
<tr>
<th>Country of admission</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
<th>2016-2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>3.6% (n=585)</td>
<td>3.8% (n=604)</td>
<td>3.4% (n=559)</td>
<td>3.6% (n=1,748)</td>
</tr>
<tr>
<td>Wales</td>
<td>2.1% (n=11)</td>
<td>2.0% (n=10)</td>
<td>4.3% (n=22)</td>
<td>2.8% (n=43)</td>
</tr>
<tr>
<td>Scotland</td>
<td>2.4% (n=36)</td>
<td>2.5% (n=35)</td>
<td>2.4% (n=33)</td>
<td>2.5% (n=104)</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>1.6% (n=9)</td>
<td>3.4% (n=18)</td>
<td>2.4% (n=12)</td>
<td>2.5% (n=39)</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>3.8% (n=53)</td>
<td>4.1% (n=60)</td>
<td>4.1% (n=59)</td>
<td>4.0% (n=172)</td>
</tr>
<tr>
<td>Total</td>
<td>3.4% (n=685)</td>
<td>3.7% (n=724)</td>
<td>3.4% (n=684)</td>
<td>3.5% (n=2,106)</td>
</tr>
</tbody>
</table>

Data are presented based on date of admission

Due to small numbers, data for non-NHS and NHS organisations in England are presented combined.

Table 4: Proportion of deaths in PICUs of all children’s deaths in the population: UK and Republic of Ireland, 2016–2018

<table>
<thead>
<tr>
<th>Country of admission</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>15.3% (n=641)</td>
<td>16.1% (n=667)</td>
<td>15.5% (n=626)*</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>18.9% (n=53)</td>
<td>23.2% (n=60)*</td>
<td>21.1% (n=59)*</td>
</tr>
</tbody>
</table>

* For 2017 and 2018, the numbers of total deaths for the Republic of Ireland and Northern Ireland are provisional and subject to change

Based on country of admission
What does this mean?

Risk of death in paediatric intensive care is low with 96.5% of patients being discharged alive between 2016 and 2018. Deaths in PICU account for about one in every six of all children’s deaths in the UK and about one in every five children’s deaths in the Republic of Ireland in any given year.

Further details

Definitions and methods

We have recorded the number of deaths in PIC by year and by country of admission for 2016 to 2018 (Table 3). The percentages in Table 3 are based on the number of admissions to PICUs over this period, not the number of individual children (i.e. if the same child had two admissions in the same time period this would count as two admissions). In Table 4, we present deaths on PICUs (2016–2018) as a proportion of all child deaths (0–15 years) in the UK and the Republic of Ireland.

Why is this important?

Death on PICU is rare and the rate of PICU death has fallen steadily since PICANet started collecting data in 2002. It is important to record the number of deaths to facilitate the investigation of mortality trends over time. It also highlights any differences in death rates between countries. Where there are very small numbers of deaths, caution should be applied when making comparisons as apparently large differences may happen by chance.
Headline figures: Unplanned extubation

What are we measuring?

Children who need help with their breathing may require a tube in their throat connected to a machine: this is called invasive ventilation. If the tube is accidentally dislodged, this is referred to as unplanned extubation. In Figure 5 and Table 5, we present the number of unplanned extubations for every thousand days of invasive ventilation that were reported in 2017 and 2018, based on country of admission. Figure 5 shows the rate of unplanned extubation by organisation for both 2017 and 2018, ranked by the 2018 rate.

What did we find?

In 2017, the number of unplanned extubations in the UK and Republic of Ireland (excluding Wales) was 255 out of a total of over 67,000 days of invasive ventilation. In 2018, this increased to 324 unplanned extubations out of a total of just over 64,000 days of invasive ventilation (excluding Wales). These figures equate to unplanned extubation rates of 3.8 (95% confidence interval: 3.3 – 4.3) and 5.1 (95% confidence interval: 4.5 – 5.6) unplanned extubations for every 1,000 days of invasive ventilation for 2017 and 2018 respectively.

Nine PICUs demonstrated a decrease in their unplanned extubation rate between 2017 and 2018, and 14 units had an increase in rate.

There were four units for which there were no unplanned extubation events reported in either 2017 or 2018. It is important to understand the reasons for these observations in terms of whether this reflects high performing units or variable standards of data reporting.

Figure 5: Unplanned extubation rates per 1,000 days of invasive ventilation by health organisation, 2017 and 2018

Ranked by unplanned extubations rate for 2018
Table 5: Frequency and rate of unplanned extubations per 1,000 days of invasive ventilation by country of admission, 2017 and 2018

<table>
<thead>
<tr>
<th>Country of admission</th>
<th>2017</th>
<th>2018</th>
<th>2017-2018</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Rate</td>
<td>Number</td>
</tr>
<tr>
<td>England</td>
<td>208</td>
<td>3.7</td>
<td>279</td>
</tr>
<tr>
<td>Wales*</td>
<td>6</td>
<td>2.6</td>
<td></td>
</tr>
<tr>
<td>Scotland</td>
<td>21</td>
<td>4.9</td>
<td>23</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>5</td>
<td>3.2</td>
<td>4</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>21</td>
<td>4.4</td>
<td>18</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>255</strong></td>
<td><strong>3.8</strong></td>
<td><strong>324</strong></td>
</tr>
</tbody>
</table>

*Due to small numbers, data for Wales are presented for 2017-2018 combined.
Due to small numbers, data for non-NHS and NHS organisations in England are presented combined.

What does this mean?

Unplanned extubation remains a relatively rare event within paediatric intensive care services with a recorded annual rate of between four and five per 1,000 days of invasive ventilation on average in 2017–2018. Most units reported unplanned extubation rates below eight per 1,000 intubated days in 2017–2018. However, this is still a relatively new data item, as units have only recently been required to report and quality assure this metric. Changes in rates of unplanned extubation should therefore be carefully monitored over the next few years.

Further details

Definitions and methods

When a child is intubated and ventilated it means that they have a tube placed in their throat attached to a machine that helps them to breathe. The machine can be used to provide different levels of oxygen to help their recovery. If the tube is accidentally removed, this is called an unplanned extubation. As we are comparing such events between PICUs, we need to calculate a rate of unplanned extubation, based on how many days of invasive ventilation are provided in each PICU, as the more patients that are ventilated on a PICU, the more likely an unplanned extubation will occur. To calculate the rate, we take the number of unplanned extubations for every 1,000 invasive ventilation days delivered. This makes comparisons between units with different volumes of invasive ventilation possible. Unplanned extubation is referred to as an ‘adverse event’. Data for this analysis were limited to 2017 and 2018 admissions only.

Why is this important?

Unplanned extubation is the most common adverse event related to airway management in intensive care: it can cause complications such as hypoxaemia (very low blood oxygen), hypercarbia (high blood carbon dioxide) and sometimes, but very rarely, death. Clearly, it is best to avoid unplanned extubation, if at all possible, but there are no established guideline levels: the NHS England service specification notes the threshold is still to be agreed. Kanthimathinathan and colleagues referred to a notional threshold equivalent to 10/1000 days. By continuously monitoring unplanned extubation rates, it may be possible to detect
when a change in practice occurred, such as the change in the adhesive tapes that caused an increase in unplanned extubation rates noted by Kanthimathinathan and colleagues\cite{1}.
Headline figures: Referral for transport

What are we measuring?
If a child needs specialist paediatric intensive care (PIC) transport, a referral is made to the PIC transport team. Sometimes the initial referral may not result in a transport, and this is called a refusal. We have recorded the number of referrals during the period 2016–2018, the number which were successful and the number which were refused. We have also looked at the reason why they were refused.

What did we find?
Over the three years 2016–2018, the details of 18,101 referrals for PIC transport were reported for those where clinicians agreed that PIC transport was required. The number of these referrals by PIC Central Transport Service (CTS) is presented by the grey bars on Figure 6. Of these, 92.1% (16,666) were accepted for transport by one of the twelve commissioned specialist paediatric intensive care (PIC) transport teams in the UK and Republic of Ireland. Around 1 in 12 (1,428) were not accepted for transport. The proportion of referrals refused for transport varied from 0% to 34% per PIC CTS – this is shown ranked by refusal rate by the orange circles on the figure. Three CTS organisations (T002, T022 and T026) reported less than a 2% refusal rate, one of which provides a service for a devolved nation. T010, that reported a 34% refusal rate, endeavours to provide a 24 hour service but this is often limited by staff availability.

Reasons for refusal include: no PIC transport team being available; the condition of the child being assessed as time critical and therefore the transport of the child could be delivered appropriately by another team; or as being ‘out of scope of care’, for example a neonatal transfer team who provide transport for small babies could more appropriately provide care.

Figure 6: Refusals following referral for urgent paediatric intensive care transport: UK and Republic of Ireland 2016–2018

T027 was established in March 2017.
What does this mean?

When a transport team receives a referral, and the specialist PIC doctor agrees that the child requires transfer from the original admitting hospital to a PICU in another hospital, they also need to confirm that the PICU has a bed available to care for the child. If a bed is not available at the nearest PICU, the PIC transport team will seek an available bed in an alternative PICU. Over the period 2016–2018, the specialist PIC transport service were able to provide a response to over 97% of requests for transport.

When the transport team refuse the referral because they are already busy with other transfers, urgent referrals may be passed to another PIC transport team, or the child may remain at the local hospital with ongoing provision of support and advice about treatment being provided by the specialist PIC transport doctor, until a staffed transport team is available.

PIC transport may also be provided for children who are transferred from one PICU to another, to another specialist service, a hospice or home.

All children requiring PIC transport (agreed by the PIC specialist doctor) will be cared for and transferred by a PIC transport service or another transport provider.

Further details

Definitions and methods

We have recorded how many children have a referral for a specialist PIC transport team to collect them and transfer them to a PICU. Where the transport does not happen, PICANet record the reasons given by the transport teams.

Why is this important?

Although only a small proportion of referrals were not accepted for urgent transfer to PIC it is important to investigate the reason for any refusals. Almost half of refusals were due to the lack of availability of a PIC team. These requests may be passed to another PIC specialist transport team or the child may remain in the care of their local hospital under close supervision from the PIC team until transport can be mobilised. However this may result in the child being moved to a PICU in another part of the country.

Delays in receiving intensive care may have clinical implications and can cause stress for the patients and their carers.

Sometimes the PIC transport team advise that the local hospital transfer the child themselves to urgently access specialist treatment e.g. a child with a serious head injury. This is recorded by PICANet as a time critical transfer. In cases where the PIC transport team assess that the specialist transport required is out of their scope of care, the transport is provided by another specialist transport team (e.g. a neonatal team providing transport for an extremely preterm infant).

The ability of a PIC transport team to transfer a child to a PICU also depends on there being a PIC bed available.
Headline figures: Bed occupancy during ‘normal hours’ and ‘out of hours’

What are we measuring?
The annual staffing study for PICANet collects information about the number of open beds in PICUs that were occupied at midday on a weekday and a weekend day during the week beginning 19 November 2018 in the UK and Republic of Ireland. The number of open beds is the number of intensive care (IC) and high dependency (HD) beds on a PICU for whom staff were available.

What did we find?
At the ‘normal hours’ census point (midday Wednesday) in 2018, at least 96% of IC beds were occupied in Scotland and over 85% in England (NHS), Northern Ireland and, the Republic of Ireland (Figure 7). HD bed occupancy ‘in normal hours’ was reported at greater than 100% in England (NHS), Wales, and the Republic of Ireland.

At the ‘out of hours’ census point at midday on a Sunday 100% IC bed occupancy was reported for Wales and the Republic of Ireland, whilst Scotland and England (NHS) remained above 80%, and Northern Ireland at 66%. ‘Out of hours’ bed occupancy for HD care was reported as over 100% for England (NHS), although lower numbers were reported for Scotland and the Republic of Ireland, with a rate of 25% being reported for Wales.

Figure 7: Percentage of funded critical care beds occupied at midday Wednesday and midday Sunday in November 2018

What does this mean?
Across the UK reported bed occupancy rates in PIC remains high both during ‘normal hours’ and ‘out of hours’. This reflects the ongoing steady increase in activity in PICUs observed.
since the start of PICANet in 2002–2003. Bed occupancy data from PICANet data have been analysed and used to inform the recent paediatric critical care review in England.

Further details

Definition and methods

Information about bed occupancy is collected each year as part of the PICANet staffing study. The survey collects details about the total number of open and funded (commissioned) intensive care and high dependency care beds, and the number of actual children being cared for on each PICU by the level of care requirement for four ‘snapshot’ time periods: a weekday; and weekend; at noon and midnight. The proportion of open and funded beds occupied during ‘normal hours’ (Wednesday at noon) and ‘out of hours’ (Wednesday at midnight, Sunday at midday and Sunday at midnight) are then calculated. In Figure 7 we present the data for midday on a Wednesday and Sunday.

Why is this important?

Information about levels of bed occupancy is important for both the commissioners and providers of PIC to ensure that there is adequate provision of paediatric critical care beds. The NHS England recent paediatric critical care review used this information to inform their review of the service. PICS standard L3 – 704 (2015) states that average bed occupancy on the unit exceeding 85% for more than two successive months should be specifically reviewed. The unit should be monitoring occupancy and there should be evidence of escalation within the Hospital and involvement of Health Boards/Commissioners if occupancy exceeds 85% for more than two successive months. Bed occupancy is also used as an NHS Services Quality Dashboard measure (PICO 5a).
Metric 1: Case ascertainment and timeliness of data submission

What are we measuring?

Case ascertainment is a measure of the proportion of total admissions that are reported to PICANet. This is one aspect of data quality. 100% ascertainment would mean we received information for all admissions.

We also measure the timeliness of data collection and present how many of the admission events are completed on the PICANet database within three months of discharge – a requirement of the PICS standards. An admission record was defined as complete when all validation checks had been fulfilled. Figure 8 shows the proportion of admission records defined as complete within three months of patient discharge in each country and Figure 9 breaks this down further to look at individual PICUs.

What did we find?

Case ascertainment

In the 16 PICUs visited in 2018, we were able to independently validate the number of PICU admissions in 14 units (87.5%). In these 14 PICUs, we found that almost all admissions (at least 97% in each unit) were reported to PICANet; five units had reported 100% of admissions. A review of the database following the validation was undertaken, resulting in the number of PICUs reporting 100% of cases increasing to eight.

Timeliness of data submission

The completeness of patients’ admission data within three months of their discharge from the unit was 83.7% for the three year period from 2016 to 2018 across the UK (excluding Northern Ireland) and Republic of Ireland (Figure 8).

Figure 8: Proportion of admission records completed within 3 months of discharge by country of admission 2016–2018

<table>
<thead>
<tr>
<th>Country of admission</th>
<th>Complete</th>
<th>Incomplete</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wales</td>
<td>98%</td>
<td></td>
</tr>
<tr>
<td>Scotland</td>
<td>97%</td>
<td></td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>84%</td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>84%</td>
<td></td>
</tr>
<tr>
<td>England NHS</td>
<td>82%</td>
<td></td>
</tr>
<tr>
<td>England non-NHS</td>
<td>81%</td>
<td></td>
</tr>
</tbody>
</table>

Northern Ireland excluded

The ‘Overall’ category takes into account all units and is not an average of the countries’ completion rates.
Northern Ireland has been excluded because data submission had to be paused due to the introduction of the General Data Protection Regulation (GDPR) such that the unit could not submit within the required timelines.

Wales and Scotland both had very timely rates of completion at around 97–98% within three months, with 80% of providers within the Republic of Ireland and England reaching completion within three months. The Republic of Ireland’s three month completion rate increased notably from 63% in the last reporting period to 84% between 2016 and 2018.

Most PICUs reported at least three quarters of data within three months of patient discharge. However, two units had less than 50% of data reported within the stipulated three month PICS standard.

Figure 9: Proportion of admission records completed within 3 months of discharge by PICU 2016–2018

Organisation ZB excluded

The ‘Overall’ category takes into account all admissions and is not an average of the units’ completion rates.
What does this mean?

High levels of case ascertainment ensure that we are confident our findings will be representative of the events and care processes that take place in PICUs. PICUs in England, Wales, Scotland and the Republic of Ireland had high or very high standards of timeliness of submission of admission data. This is reflected in most units reporting the majority of their data within 3 months of patient discharge, although there were a small number of units which exhibited low rates of timely completion.

Further details

Definitions and methods

Every PICU receives a validation visit from the PICANet research nurse on a rolling programme. At those visits, the numbers of admissions recorded locally are compared with the numbers held on the PICANet database. Any discrepancies are followed up by the PICU. This is called an ascertainment check. Not every PICU is visited each year, so our ascertainment check is based on those PICUs that have received a visit in the most recent year of the reporting period. We also monitor the timeliness of data completion, benchmarking against the PICS standard for reporting admissions to PICANet within three months of discharge from the unit.

Why is this important?

We want to base our analyses on all admissions to be sure that we can interpret our findings appropriately. If a significant proportion of admissions is missing we cannot be as confident about our conclusions. For example, if a number of admissions of children who had died on PICU were missing, we may make the wrong conclusion when comparing standardised mortality ratios (SMRs) between PICUs. Our high ascertainment rate therefore means that we can be confident about our findings.

As well as ensuring we collect data on as many admissions as possible, we also want to ensure that data are collected in a timely manner, that data are accurate and that all relevant data are available for analysis.
Metric 2: Retrieval mobilisation times

What are we measuring?

Some children need to be transported to a PICU in a different hospital for urgent care (non-elective transports). For 2018, we have calculated how long it takes for the PIC centralised transport service (CTS) team to start their journey to pick up a child who needs urgent PIC following a clinical decision that PIC transport is required. The proportion of these journeys that started within 30 minutes, 31 to 60 minutes, 61 to 180 minutes, and over 180 minutes are presented for 2018 for the UK and Republic of Ireland overall. This information is summarised for the individual PIC transport teams.

What did we find?

More than half of the 12 organisations (T001, T002, T003, T004, T005, T008 and T024) mobilised within 30 minutes for more than half of the journeys. Of the specialist PIC transport services, half of the 12 organisations mobilised their team within 1 hour for more than three quarters of urgent transports in 2018 (Figure 10).

Out of a total of 4,224 journeys, just under three fifths (58.9%) were started within 30 minutes, with just over 3 in 4 journeys (76.7%) started within one hour after the decision was made that the child required urgent transport (Figure 11). Just over 1 in 20 journeys (5.9%) started more than three hours after this decision.

Figure 10: Proportion of non-elective transports mobilised by PICU CTS team by time to mobilisation: UK and Republic of Ireland, 2018

Organisations are ranked by the NHS England 30 minute target, from which Northern Ireland, Scotland, Wales and Republic of Ireland are exempt.
What does this mean?

In the vast majority of cases, PIC CTS teams take less than an hour to start their journey to pick up a child who requires urgent critical care. The NHS England Quality Dashboard recommends that the team departs the transport base within 30 minutes from the time the referral is accepted for retrieval. Most PIC CTS teams aim to depart base within 30 minutes of accepting a child for urgent transport. In those cases where it takes longer for the team to depart, the reason for this may relate to the availability of staff, a transport vehicle or a PICU bed.

At busy times identifying an available paediatric intensive care bed may delay departure and some journeys require road and air transport which also require additional planning before the team can depart.

Further details

Definitions and methods

Once a specialist transport organisation has agreed to transport a child they have a target set by the Care Quality Commission to start their journey within one hour and NHS England Quality Dashboard monitors the percentage of emergency retrievals undertaken where the team departs the transport base within 30 minutes from the time the referral is accepted for retrieval. Standards for mobilisation time have not been defined for the devolved nations and ROI. We measured the time from when the team agreed to the transport to the time they set off in the ambulance (or helicopter / plane) for what are called ‘non-elective’ or urgent transports – these are not planned transfers from one PICU to another or from a PICU to a district general hospital.

Why is this important?

Any delay in receiving intensive care could put the sick child at risk, as the referring hospital may not have the resources to look after a critically ill child. Delays in getting the team mobilised may just mean that it is very busy, e.g. during periods of ‘winter pressures’. Persistent delays may mean that there are insufficient resources in the transport organisation or there are some other organisational issues that need to be addressed. By measuring the time it takes to mobilise the transport team continuously over a long period of time PICANet are able to monitor and report back on PIC CTS performance, enabling the transport organisations to make changes to improve the quality of their service if appropriate.
Metric 3: Number of nurses providing clinical care per bed

What are we measuring?

In November of each year, we ask PICUs to record how many clinically qualified nurses and non-registered health care staff are employed on their PICU: both their establishment (i.e. total funded posts); and any vacant posts.

The Paediatric Intensive Care Society (PICS) Standards state a minimum number of 7.01 Whole Time Equivalent (WTE) qualified (registered) nurses are needed to staff one level 3 critical care bed (2015). Non-registered staff with appropriate competencies may be included in calculations of staffing levels per child requiring critical care, so long as they are working under direct supervision of a registered nurse at all times. Previous PICS Standards (2010) endorsed the benchmark of 6.4 WTE qualified nurses to staff one level 3 critical care bed.

What did we find?

Overall, the establishment figures for PICUs across the UK and the Republic of Ireland show that in 2018 few units achieved either of the PICS standards. Five (15%) PICUs met 7.01 WTEs per bed; this increased to eight (24%) when non-registered health care staff (Bands 2-4) providing clinical care were included (Figure 12). Twelve (36%) PICUs met the previous standard of 6.4 WTEs (2010), without including non-registered staff.

However if all the recorded vacancies for qualified nurses and non-registered health care staff working clinically were filled, 13 (39%) PICUs would meet the standard of 7.01 WTEs per bed and 20 (60%) would meet the previous standard of 6.4 WTE.

Figure 12: Number of clinically qualified nurses and non-registered staff providing clinical care in post (WTE) per bed by health organisation, 2018
What does this mean?

Based on the data provided by UK and Republic of Ireland PICUs in November 2018, a quarter of PICUs met the recommended standard of the Paediatric Intensive Care Society. The addition of bands 2-4 delivering clinical care has enabled three PICUs to meet this standard. However, despite few PICUs meeting these standards, staffing data from the census shows that the units ensure that their staffing levels are appropriate for the number of children on the unit and their care requirements. This may be achieved by unit staff working flexibly, undertaking additional shifts or using bank or agency staff. These data should be used to inform the future planning of PIC.

Further details

Definition and methods

Each year PICANet carries out a staffing study to monitor staffing levels within PICUs and to audit the appropriate standards of the Paediatric Intensive Care Society: currently the PICS Quality Standards for the Care of Critically Ill Children (5th Edition, December 2015). Staffing data are collected in the November of each year: for the week beginning 19 November in 2018, we present the percentage of PICUs meeting the recommended level of nurse staffing per funded critical care bed.

The recommended number of nurses required (or nurse staffing establishment), in order to provide the appropriate levels of care for the number and given dependency of the bed, is calculated according to the PICS Standards for Intensive Care (one nurse to one bed) and high dependency (one nurse for every two beds).

Why is this important?

PICUs need to be able to monitor whether they have adequate nursing staff available to run their unit efficiently. PICS Standard L3-207 and guidance from the PICS Nurse Workforce Planning document for Level 3 Paediatric Critical Care Units, October 2016 states that ‘the minimum number of qualified nurses required to staff one level 3 critical care bed is a minimum of 7.01 WTE’. Non-registered staff (health care assistants) with appropriate competencies may be included in calculations of staffing levels per child requiring critical care so long as they are working under direct supervision of a registered nurse at all times.

The availability of specialist PIC nurses is affected by many factors external to PIC including nursing salaries and the cost of living in capital cities. Staff recruitment and retention is currently under review as part of the paediatric critical care review. Some PICUs are developing the role of band 2–4 health care assistants to support qualified staff in delivering clinical care in critical care units.
Metric 4: Emergency readmissions within 48 hours

What are we measuring?

For each PICU, we record the frequency of emergency readmissions within 48 hours of discharge in comparison to the average for the UK and Republic of Ireland (Table 6). This is calculated using the admission and discharge dates and times. The emergency readmission rate for each nation was calculated by dividing the number of emergency readmissions by the total number of admissions occurring in that nation for a given year.

We also consider relative emergency readmission rates; these allow us to compare each PICU’s rate of emergency readmission within 48 hours with the equivalent rate over the UK and Republic of Ireland combined (Figure 13), by dividing their 48 hour emergency readmission rate by the combined UK and Republic of Ireland rate. Relative readmission rates higher than one indicate that a unit has a higher rate of emergency readmissions within 48 hours than the overall rate for the UK and Republic of Ireland.

What did we find?

Around 330 children per year (or 1.7 out of every 100 admissions) were discharged from PICU, but then readmitted as an emergency within 48 hours (Table 6). Rates of emergency readmissions varied by country with Scotland having slightly higher rates throughout the reporting period of 2.5% in 2016 and 2017 and 2.0% in 2018. The rates in the Republic of Ireland and English NHS units were steady, at around 1.6% for England and 1.4% for the Republic of Ireland. Northern Ireland and Wales both saw increases in the rate of emergency readmissions within 48 hours in 2018 compared to the two earlier years, although numbers were very small.

Table 6: Number of emergency readmissions within 48 hours 2016–2018

<table>
<thead>
<tr>
<th>Country</th>
<th>2016</th>
<th>2017</th>
<th>2018</th>
<th>2016-2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>253 (1.6%)</td>
<td>269 (1.7%)</td>
<td>262 (1.6%)</td>
<td>784 (1.6%)</td>
</tr>
<tr>
<td>Wales</td>
<td>6 (1.1%)</td>
<td>5 (1.0%)</td>
<td>16 (3.1%)</td>
<td>27 (1.8%)</td>
</tr>
<tr>
<td>Scotland</td>
<td>37 (2.5%)</td>
<td>35 (2.5%)</td>
<td>27 (2.0%)</td>
<td>99 (2.3%)</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>10 (1.8%)</td>
<td>5 (1.0%)</td>
<td>17 (3.4%)</td>
<td>32 (2.0%)</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>21 (1.5%)</td>
<td>20 (1.4%)</td>
<td>18 (1.3%)</td>
<td>59 (1.4%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>325 (1.6%)</td>
<td>331 (1.7%)</td>
<td>339 (1.7%)</td>
<td>1001 (1.7%)</td>
</tr>
</tbody>
</table>

Due to small numbers, data for non-NHS and NHS organisations in England are presented combined.

The emergency readmission rate for each PICU over this period ranged from 0.2 to 1.6 times the overall UK and Republic of Ireland rate. We would expect to see substantial variation in each PICU because of the low number of emergency admissions within 48 hours within each individual unit.

Looking at each of the organisations individually (Figure 13), 11 PICUs consistently had lower rates of emergency readmissions within 48 hours than the combined rate, whereas six PICUs consistently had higher rates.
Figure 13: Relative rate of emergency readmission within 48 hours of discharge by PICU 2016–2018

Emergency readmission rates for each individual unit are relative to the overall rate of 1.66, the horizontal dotted line shows where a bar would sit if a unit had an emergency readmission rate that was exactly the same as the overall rate.

What does this mean?

The proportion of patients requiring emergency re-admission within 48 hours of discharge from PICU was low in all countries, with around 1.7 per 100 admissions. There was substantial variation in the relative emergency readmission rate between PICUs and within PICUs year on year.

Further details

Definitions and methods

We defined an emergency readmission within 48 hours as any unplanned admission to the same PICU within 48 hours of their last discharge from PICU. So if a child was admitted on 1 March at 12:00 and discharged on 2 March at 17:00, but then admitted as an emergency (an unplanned admission) before 4 March at 17:00, they would have been counted in our analysis as they returned to PICU within 48 hours. We then calculated the number of emergency readmissions within 48 hours for every 100 admissions in each PICU to give a rate per 100 admissions. This allows us to compare PICUs with different numbers of admissions.

There is no standard set for the acceptable rate of emergency readmissions within 48 hours, so in order to calculate relative rates we used the overall readmission rate for each specific year based on all PICUs contributing to PICANet as the standard. We then compared the 48 hour emergency readmission rate for each individual PICU to this overall rate. When interpreting the data, PICUs with relative readmission rates below one have a lower readmission rate than that seen in the UK and Republic of Ireland combined and PICUs with a relative rate above one have a higher readmission rate.
Why is this important?

Emergency readmission within 48 hours is an undesirable outcome. From an individual child’s perspective, it suggests that their health has deteriorated in a short space of time and that they require further intensive care treatment. This will cause stress to the child, their families and their carers. For a busy PICU, each admission also creates additional demand on a service that usually operates close to capacity.

It should be noted that although emergency readmission is used as a quality indicator, we do not know the cause of the readmission. PICANet is therefore unable to assess whether the child was discharged too early, or into the wrong care environment, or whether the need for future intensive care was not foreseen.

Relative rates of emergency readmission within 48 hours compared with the overall rate for the UK and Republic of Ireland show considerable variation year on year, although some of this variation could be due to small numbers of emergency readmissions within 48 hours in each PICU. This suggests that emergency readmission rates should be monitored on an ongoing basis.
Metric 5: Mortality in PICU

What are we measuring?
Mortality (death) rates are assessed for every PICU based on a statistical approach that accounts for the severity of the child’s illness at the time of admission. This method is known as risk adjustment. The number of children who actually die (the ‘observed’ number) is compared to the number we predict to die (the ‘expected’) to derive the risk-adjusted Standardised Mortality Ratio (SMR). The risk-adjustment method used to calculate expected mortality was the Paediatric Index of Mortality 3 (PIM3)\(^3\), which has been recalibrated, based on the data within this reporting period. Further details on recalibration can be found in the Tables and Figures document.

What did we find?
The risk-adjusted SMR for each PICU in the UK and Republic of Ireland is plotted in Figure 14 according to the number of admissions for the period from 2016 to 2018. There was no evidence that any PICU had an excess mortality rate compared to what we would expect during the three year reporting period.

Figure 14: Risk-adjusted Standardised Mortality Ratio (SMR) by health organisation 2016–2018
What does this mean?

Compared with overall mortality for the UK and Republic of Ireland there were no PICUs for which mortality rates were higher than expected during the three year reporting period, after allowing for the level of sickness of the patient at the time of admission.

How to read a funnel plot

Figure 15 is a simple example of what a funnel plot might look like. The ‘funnel’ is created using statistical methods that tell us what range of values we might expect for mortality, given that there are normal ‘ups and downs’ (natural variation). The limits are wider where there are fewer admissions because with only a few observations we cannot be as certain about our findings. With more observations we can be more confident that the outcome is likely to fall within narrower limits.

The blue dots represent individual PICUs. They are plotted from left to right (horizontal-axis) based on the number of admissions to each PICU.

The blue line in the middle of the funnel represents what is “expected”, in other words if a dot were to fall exactly on this line then this would mean that the number of deaths observed and the number of expected deaths are equal to each other (so there are no more or fewer deaths than we anticipate). It would be quite rare for a dot to fall exactly on this line and you would always expect a scatter of dots above and below this line. The whole point about funnel plots is to allow us to see differences between units taking into account natural variation.

Any dot that falls within the funnel shape is within the limits of what we would expect to see so the number of observed deaths is no greater (or smaller) than the number we expect. We therefore have no concerns about PICUs with blue dots within the ‘funnel’.

If a dot is above the funnel shape (like the red dot in Figure 15) we say that it is outside the upper limit and is a ‘statistical outlier’. This means that the number of deaths in the PICU are higher than the number we expect and that this is possible due to a cause other than natural variation. There are many reasons that a PICU could have a dot which lies above the upper limit including the fact we may not have properly accounted for how sick patients are when they enter the ward, or purely due to chance alone. We have a specifically designed process for investigating whether these PICUs really do have a higher number of deaths than expected and is a ‘true outlier’.
Further details

Definitions and methods

Clinical data collected on admission are used in a statistical model to predict the probability that each child might die in PICU: the worse a patient’s clinical condition is on admission, the higher the probability that they might die. These probabilities are added up for each PICU to give an overall expected number of deaths in any one period. We then count the actual (observed) number of deaths and calculate what is called a Standardised Mortality Ratio (SMR) by dividing the observed number of deaths by the expected number. We then use the funnel plot to assess the level of mortality in the PICUs against what is expected.

Why is this important?

Although death whilst receiving care on a PICU is extremely rare, it is important to assess whether more (or fewer) deaths than expected occur, as this can indicate that there is something different happening in a PICU. It only represents a statistical measure of mortality and it is very important to use this as an indicator that further investigation is required, not as a true measure of the quality of care delivered.
Variation in levels of care provision in designated PICUs from 2010 to 2018

Introduction

Paediatric critical care is a highly specialised service, costing around £230 million a year to save the lives of children. The recent Paediatric Critical Care and Surgery in Children Review (NHS England, 2017) utilised data supplied by PICANet and demonstrated the increasing pressure on the Paediatric Intensive Care service, whilst maintaining high quality outcomes. This review also highlighted variation within units and the changing nature of service provision such as: the increasing levels of morbidity among children and the care for children receiving long term ventilation.

PICANet has been collecting data about paediatric intensive care provision across the UK and ROI since 2002 (Additional information can be found in the Background section on page 61 for the start dates for data collection across the countries of the UK and for ROI). This audit monitors variations in care provision, service demand and the increase in the number of commissioned high dependency beds within designated Paediatric Intensive Care Units who report all their activity.

In this chapter, we build on some of the work carried out for the Paediatric Critical Care and Specialised Surgery in Children Review to examine the variation in care provision between designated PICUs across the UK and ROI including changes in the levels of care provision over the period 2010–2018.

Method

Three types of PICU were defined using a hierarchy determined by their level of care provision (Table 7).

Table 7: Paediatric Intensive Care Unit type and their levels of care provision

<table>
<thead>
<tr>
<th>Type of PICU</th>
<th>Level of care provision</th>
<th>PICANet units</th>
</tr>
</thead>
<tbody>
<tr>
<td>PICU / ECMO</td>
<td>PICUs providing cardiac/respiratory Extracorporeal Membrane Oxygenation (ECMO) or Extracorporeal Life Support (ECLS)</td>
<td>12</td>
</tr>
<tr>
<td>PICU / HD</td>
<td>PICUs delivering both intensive care and high dependency care in a single unit</td>
<td>14</td>
</tr>
</tbody>
</table>

There have been changes in the category of care provision by some units over the period 2010 to 2018, and so PICUs have been categorised by type for the latter period of the analysis i.e. 2016–2018. Those units solely providing private healthcare have been excluded from these analyses.

PICANet admission event data are collected for all children admitted to designated PICUs across the UK and ROI. Data are presented for admissions and the number of bed days by triennia for the period 2010 to 2018 by PICU type. Admissions and bed days were further investigated to identify differences in the highest level of care provision and number of bed days using a hierarchy of respiratory support (as a proxy for level of critical care) by PICU type over time. Respiratory support has been categorised as follows: ECMO; Invasive Ventilation; Non Invasive Ventilation; High Flow Nasal Cannula Therapy (HFNCT) and no
respiratory support. This information is presented by PICU type including summary statistics for each group to illustrate the variation between individual PICUs.

Detailed information concerning levels of care has been defined using Healthcare Resource Groups (HRGs). Healthcare Resource Groups are standard groupings of clinically similar treatments which categorise comparable levels of healthcare resource use within the NHS to assign the cost of PIC care provision. HRG groupings are described in Table 8. This information was not collected for the whole period of this analysis. These data were not submitted for all hospitals until 2016. HRG data are therefore presented for the last three year period alone (2016–2018) by PICU type for the highest HRG level of care for admissions and the total number of bed days for each HRG category.

Table 8: Definition of Healthcare Resource Groups

<table>
<thead>
<tr>
<th>Healthcare Resource Group</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>XB09Z Enhanced Care</td>
<td>Care provided at a level below basic critical care</td>
</tr>
<tr>
<td>XB07Z High Dependency</td>
<td>Basic critical care – monitoring and interventions</td>
</tr>
<tr>
<td>XB06Z High Dependency Advanced</td>
<td>Intermediate critical care – monitoring and interventions</td>
</tr>
<tr>
<td>XB05Z Intensive Care Basic</td>
<td>Invasive ventilatory support and/or support for two or more organ systems</td>
</tr>
<tr>
<td>XB04Z Intensive Care Basic Enhanced</td>
<td>Invasive ventilatory support and/or support for two or more organ systems</td>
</tr>
<tr>
<td>XB03Z Intensive Care Advanced</td>
<td>Complex interventions/organ support</td>
</tr>
<tr>
<td>XB02Z Intensive Care Advanced Enhanced</td>
<td>Complex interventions/organ support</td>
</tr>
<tr>
<td>XB01Z Intensive Care ECMO/ECLS</td>
<td>ECMO and ECLS support</td>
</tr>
</tbody>
</table>

Results

Paediatric intensive care activity 2010–2018

Over the nine-year period 2010 to 2018, there were 176,338 separate admissions to designated PICUs across the UK and ROI. Table 9 shows the number of admissions to paediatric intensive care and the number of bed days provided by the three types of PICU for the three triennia: 2010–2012, 2013–2015 and 2016–2018.

Table 9: Admissions & activity by Paediatric Intensive Care Unit type 2010–2018

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
</tr>
<tr>
<td>PICU / ECMO (n=12)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions</td>
<td>30,677</td>
<td>54.0</td>
<td>31,103</td>
<td>52.7</td>
</tr>
<tr>
<td>Bed days</td>
<td>160,546</td>
<td>56.8</td>
<td>184,532</td>
<td>56.6</td>
</tr>
<tr>
<td>PICU (n=4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions</td>
<td>6,962</td>
<td>12.3</td>
<td>7,150</td>
<td>12.1</td>
</tr>
<tr>
<td>Bed days</td>
<td>34,531</td>
<td>12.2</td>
<td>39,353</td>
<td>12.1</td>
</tr>
<tr>
<td>PICU / HD (n=14)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions</td>
<td>19,178</td>
<td>33.8</td>
<td>20,716</td>
<td>35.1</td>
</tr>
<tr>
<td>Bed days</td>
<td>87,470</td>
<td>31.0</td>
<td>102,176</td>
<td>31.3</td>
</tr>
<tr>
<td>All PICUs (n=30)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions</td>
<td>56,817</td>
<td>32.2</td>
<td>58,969</td>
<td>33.4</td>
</tr>
<tr>
<td>Bed days</td>
<td>282,547</td>
<td>29.3</td>
<td>326,061</td>
<td>33.8</td>
</tr>
</tbody>
</table>
Overall admissions for PIC have increased over the period 2010 to 2018 from 56,817 in 2010 to 2012 to 60,662 in 2016 to 2018, an increase of 6.8%. However, this translates into a 26.3% increase in the activity of PICUs in the UK and ROI from 282,547 bed days in 2010 to 2012 to 356,736 bed days in 2016 to 2018.

To investigate the distribution of PIC care provision by PICU type over this period, Figure 16 shows the trends in care provision over time. The proportion of overall PICU admissions in PICUs delivering ECMO has reduced over time from 54% in 2010 to 2012 to 49.3% in 2016 to 2018 mirrored by a reduction in the overall proportion of bed days provided by these units over the same period: 56.8% in 2010 to 2012 to 52.3% in 2016 to 2018, although this represents an overall increase of almost 27,500 additional days of care on PICU / ECMO units. The opposite is seen for PICUs with both IC and HD designated beds with admissions to these units increasing from 33.8% in 2010 to 2012 to 39.0% in 2016 to 2018 and the overall proportion of bed days increasing from 31.0% to 35.7% over the same period. This represents an increase of 45.6% of the bed days provided by PICU / HD units, 39,846 bed days. The proportion of admissions and bed days to PICUs with IC designated beds alone remained stable over this period for both measures at around 12%.

**Figure 16: Proportion of care provision by Paediatric Intensive Care Unit type by triennia 2010–2018**

![Proportion of care provision by Paediatric Intensive Care Unit type by triennia 2010–2018](image)

**Trends in paediatric intensive care provision**

To investigate trends in the level of PIC provision by the different types of PICU over the period 2010 to 2018, a hierarchy of respiratory support is presented as a proxy for level of care. First, the number and proportion of admissions are presented by the highest level of respiratory support required during each admission (Table 10) and then the total number of bed days provided at each level of respiratory support (Table 11). Each table shows the number and proportion of admissions or bed days provided by type of PICU and level of respiratory support for each triennia as well as describing the variation by individual units within each PICU type in the form of a median proportion and range.
### Table 10: Trends in admissions by level of respiratory support 2010–2018

<table>
<thead>
<tr>
<th></th>
<th>PICU / ECMO</th>
<th>PICU</th>
<th>PICU / HD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2010–2012</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ECMO</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>587 (1.9)</td>
<td>14 (0.2)</td>
<td>&lt;3 (0.0)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>1.0 (0.2–14.4)</td>
<td>0.0 (0.0–0.4)</td>
<td>†</td>
</tr>
<tr>
<td><strong>Invasive ventilation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>22,792 (74.3)</td>
<td>4,838 (69.5)</td>
<td>10,293 (53.7)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>76.7 (49.4–84.0)</td>
<td>58.2 (55.0–86.6)</td>
<td>55.6 (27.3–83.4)</td>
</tr>
<tr>
<td><strong>Non-invasive ventilation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>1,270 (4.1)</td>
<td>325 (4.7)</td>
<td>1,242 (6.5)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.7 (18.8–7.8)</td>
<td>4.1 (2.7–9.1)</td>
<td>5.4 (2.8–15.4)</td>
</tr>
<tr>
<td><strong>High flow nasal cannula therapy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>- -</td>
<td>- -</td>
<td>- -</td>
</tr>
<tr>
<td><strong>Nil</strong></td>
<td>6,004 (19.6)</td>
<td>1,785 (25.6)</td>
<td>7,595 (39.6)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>16.3 (9.1–45.0)</td>
<td>35.1 (9.0–42.3)</td>
<td>37.8 (13.8–57.4)</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>30,677 (100.0)</td>
<td>6,962 (100.0)</td>
<td>&lt;19,179 (100.0)</td>
</tr>
<tr>
<td><strong>2013–2015</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ECMO</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>696 (2.2)</td>
<td>15 (0.2)</td>
<td>5 (0.0)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>1.5 (0.5–12.6)</td>
<td>0.1 (0.0–0.4)</td>
<td>0.0 (0.0–0.1)</td>
</tr>
<tr>
<td><strong>Invasive ventilation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>22,680 (72.9)</td>
<td>4,723 (66.1)</td>
<td>10,900 (52.6)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>76.4 (44.0–83.4)</td>
<td>59.1 (51.4–79.4)</td>
<td>51.3 (33.5–78.7)</td>
</tr>
<tr>
<td><strong>Non-invasive ventilation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>1,338 (4.3)</td>
<td>424 (5.9)</td>
<td>1,540 (7.4)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>4.3 (1.3–7.0)</td>
<td>6.3 (4.0–9.9)</td>
<td>7.2 (4.0–22.4)</td>
</tr>
<tr>
<td><strong>High flow nasal cannula therapy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>283 (0.9)</td>
<td>45 (0.6)</td>
<td>422 (2.0)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>0.8 (0.0–2.7)</td>
<td>1.2 (0.3–1.5)</td>
<td>1.2 (0.0–8.4)</td>
</tr>
<tr>
<td><strong>Nil</strong></td>
<td>6,099 (19.6)</td>
<td>1,941 (27.1)</td>
<td>7,849 (37.9)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>16.0 (8.6–45.1)</td>
<td>30.8 (16.0–43.3)</td>
<td>34.4 (13.8–52.8)</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>31,103 (100.0)</td>
<td>7,150 (100.0)</td>
<td>20,716 (100.0)</td>
</tr>
<tr>
<td><strong>2016–2018</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ECMO</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>730 (2.4)</td>
<td>7 (0.1)</td>
<td>7 (0.0)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>1.7 (0.9–10.1)</td>
<td>0.0 (0.0–0.2)</td>
<td>0.0 (0.0–0.2)</td>
</tr>
<tr>
<td><strong>Invasive ventilation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>21,857 (73.3)</td>
<td>4,474 (63.2)</td>
<td>11,264 (47.6)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>75.9 (51.4–83.6)</td>
<td>56.7 (46.4–76.3)</td>
<td>46.9 (20.1–78.5)</td>
</tr>
<tr>
<td><strong>Non-invasive ventilation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>1,191 (4.0)</td>
<td>414 (5.8)</td>
<td>2,114 (8.9)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.0 (0.5–8.7)</td>
<td>6.3 (3.6–11.2)</td>
<td>6.9 (2.0–21.0)</td>
</tr>
<tr>
<td><strong>High flow nasal cannula therapy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admissions (%)</td>
<td>1,046 (3.5)</td>
<td>337 (4.8)</td>
<td>1,336 (5.7)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.4 (0.0–10.8)</td>
<td>6.7 (2.0–7.3)</td>
<td>4.5 (0.1–13.7)</td>
</tr>
<tr>
<td><strong>Nil</strong></td>
<td>4,999 (16.8)</td>
<td>1,852 (26.1)</td>
<td>8,924 (37.7)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>15.0 (8.2–31.2)</td>
<td>28.3 (17.9–39.1)</td>
<td>39.4 (15.3–51.9)</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>29,823 (100.0)</td>
<td>7,084 (100.0)</td>
<td>23,645 (100.0)</td>
</tr>
</tbody>
</table>

Units with no patients in a given ventilation category are included in the summary statistic calculations
* Includes children with unknown ventilation status; † omitted due to small number suppression
Variation in levels of care provision in designated PICUs from 2010 to 2018

<table>
<thead>
<tr>
<th></th>
<th>PICU / ECMO</th>
<th>PICU</th>
<th>PICU / HD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2010–2012</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECMO</td>
<td>10,833 (6.7)</td>
<td>33 (0.1)</td>
<td>186 (0.2)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.8 (1.0–37.9)</td>
<td>0.1 (0.0–0.2)</td>
<td>0.0 (0.0–3.1)</td>
</tr>
<tr>
<td>Invasive ventilation</td>
<td>137,273 (85.5)</td>
<td>31,143 (90.2)</td>
<td>71,059 (81.2)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>89.0 (58.8–92.1)</td>
<td>85.2 (83.2–96.1)</td>
<td>82.3 (48.3–95.1)</td>
</tr>
<tr>
<td>Non-invasive ventilation</td>
<td>4,676 (2.9)</td>
<td>1,087 (3.1)</td>
<td>4,915 (5.6)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>2.8 (0.5–4.5)</td>
<td>3.0 (1.9–7.9)</td>
<td>4.4 (1.1–22.6)</td>
</tr>
<tr>
<td>High flow nasal cannula therapy</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>- -</td>
<td>- -</td>
<td>- -</td>
</tr>
<tr>
<td>Nil</td>
<td>7,731 (4.8)</td>
<td>2,268 (6.6)</td>
<td>11,241 (12.9)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.6 (1.3–12.4)</td>
<td>10.2 (1.9–12.2)</td>
<td>11.9 (3.1–29.0)</td>
</tr>
<tr>
<td>Overall*</td>
<td>160,546 (100.0)</td>
<td>34,531 (100.0)</td>
<td>87,470 (100.0)</td>
</tr>
<tr>
<td><strong>2013–2015</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECMO</td>
<td>15,252 (8.3)</td>
<td>57 (0.1)</td>
<td>180 (0.2)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>5.1 (1.0–38.7)</td>
<td>0.1 (0.0–0.2)</td>
<td>0.0 (0.0–1.1)</td>
</tr>
<tr>
<td>Invasive ventilation</td>
<td>153,792 (83.3)</td>
<td>34,557 (87.8)</td>
<td>80,638 (78.9)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>85.0 (58.7–93.2)</td>
<td>84.5 (81.4–92.2)</td>
<td>80.0 (61.2–92.6)</td>
</tr>
<tr>
<td>Non-invasive ventilation</td>
<td>6,299 (3.4)</td>
<td>1,578 (4.0)</td>
<td>7,825 (7.7)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.1 (0.4–5.5)</td>
<td>4.5 (2.6–8.2)</td>
<td>7.0 (3.1–25.3)</td>
</tr>
<tr>
<td>High flow nasal cannula therapy</td>
<td>763 (0.4)</td>
<td>93 (0.2)</td>
<td>1,507 (1.5)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>0.3 (0.0–1.6)</td>
<td>0.4 (0.0–0.6)</td>
<td>1.0 (0.0–6.9)</td>
</tr>
<tr>
<td>Nil</td>
<td>8,359 (4.5)</td>
<td>3,067 (7.8)</td>
<td>12,026 (11.8)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.9 (1.8–11.0)</td>
<td>8.5 (5.0–13.6)</td>
<td>10.7 (3.0–22.6)</td>
</tr>
<tr>
<td>Overall*</td>
<td>184,532 (100.0)</td>
<td>39,353 (100.0)</td>
<td>102,176 (100.0)</td>
</tr>
<tr>
<td><strong>2016–2018</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECMO</td>
<td>17,320 (9.2)</td>
<td>43 (0.1)</td>
<td>60 (0.0)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>7.3 (2.2–33.0)</td>
<td>0.1 (0.0–0.2)</td>
<td>0.0 (0.0–0.9)</td>
</tr>
<tr>
<td>Invasive ventilation</td>
<td>154,669 (82.3)</td>
<td>35,822 (86.5)</td>
<td>98,056 (77.0)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>80.8 (62.8–93.3)</td>
<td>83.0 (77.6–91.6)</td>
<td>74.6 (38.6–94.9)</td>
</tr>
<tr>
<td>Non-invasive ventilation</td>
<td>5,981 (3.2)</td>
<td>1,854 (4.5)</td>
<td>10,596 (8.3)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>2.1 (0.1–6.4)</td>
<td>5.2 (3.2–8.4)</td>
<td>6.3 (1.7–27.9)</td>
</tr>
<tr>
<td>High flow nasal cannula therapy</td>
<td>2,759 (1.5)</td>
<td>955 (2.3)</td>
<td>4,389 (3.4)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>1.4 (0.0–5.4)</td>
<td>3.2 (1.0–4.5)</td>
<td>2.4 (0.0–11.9)</td>
</tr>
<tr>
<td>Nil</td>
<td>7,260 (3.9)</td>
<td>2,757 (6.7)</td>
<td>14,215 (11.2)</td>
</tr>
<tr>
<td>Median proportion (range)</td>
<td>3.2 (1.6–7.3)</td>
<td>6.6 (4.0–13.3)</td>
<td>11.2 (3.4–21.6)</td>
</tr>
<tr>
<td>Overall*</td>
<td>187,989 (100.0)</td>
<td>41,431 (100.0)</td>
<td>127,316 (100.0)</td>
</tr>
</tbody>
</table>

Units with no patients in a given ventilation category are included in the summary statistic calculations

*Includes children with unknown ventilation status
ECMO is a relatively rare mode of treatment. Virtually all ECMO provision is carried out in PICU / ECMO units (i.e. those providing paediatric cardiac surgery), where admissions have shown a small increase over time, with the proportion of the total admissions supported on PICU / ECMO increasing by nearly 25% from 587 in 2010–2012 to 730 in 2016–2018 (Table 10). As a proportion of the activity provided by a PICU / ECMO unit, ECMO bed days have increased by almost 60% (10,833 in 2010–2012; 17,320 in 2016–2018) consisting of 9.2% of all bed days in these units by 2016–2018 (Table 11).

Children receiving invasive ventilation are the largest proportion of all admissions by respiratory support for all types of PICU, when grouped together. The PICU / ECMO units have the highest proportion of admissions with invasive ventilation as their highest level of respiratory support at 74.3% in 2010–2012 which remained relatively stable at 73.3% in 2016–2018. The proportion of bed days for children who required invasive ventilation followed a similar pattern with 85.5% of unit activity provided for this group in 2010–2012 and 82.3% in 2016–2018. Around half (53.7%) of admissions to PICU / HD units in 2010–2012 received invasive ventilation as their highest level of respiratory support which showed a reduction to 47.6% in 2016–2018. However around four fifths (81.2%) of the bed days in PICU / HD units were for children requiring invasive ventilation in 2010–2012, and this proportion remained fairly stable over time at 77.0% in 2016–2018.

High flow nasal cannula therapy (HFNCT) was introduced gradually across PICUs, and by 2016–2018, for around 5% of admissions to all types of PICU, this was the maximum level of respiratory support required. However, despite also being used as a step-up or step-down for children requiring more advanced levels of respiratory support, HFNCT still only accounted for about 2.5% of all bed days within PICU.

The proportion of admissions with no requirement for respiratory support has shown little change over time: from around one fifth (19.6%) of admissions in 2010–2012 to 16.8% in 2016–2018 for PICU / ECMO units. This remained at around one quarter of all admissions to PICUs with only designated intensive care beds over the period, and about two fifths for PICU / HD units (39.6% in 2010–2012; 37.7% in 2016–2018). Children with no respiratory support requirement constitute a much lower proportion of bed days for PICU / HD units (12.9% in 2010–2012; 11.2% in 2016–2018), and the actual number of bed days has remained relatively static for both this group and the PICU only group units. However among the PICU / HD group, whilst the number of admissions not requiring any respiratory support has increased by 17.5% between the 2010–2012 and 2016–2018 periods, the number of bed days for patients receiving no respiratory support increased by 26.5% (11,241 in 2010–2012; 14,215 in 2016–2018).

### Variation in paediatric intensive care provision by HRG by PICU type

The highest HRG level of care during an admission for all PICUs grouped by type for the period 2016 to 2018 is presented in Figure 17. There was wide variation in the proportion of the highest level of HRG provided by PICUs both between the groups and even within each type.

Overall, the highest level of HRG for PICUs providing ECMO (those units providing the highest levels of intensive care) was defined as “Intensive Care ECMO” (XB01Z) for 2.7% of admissions, but this ranged from 0.9 to 12.8%. Similarly, admissions defined as “Intensive Care Advanced Enhanced” (XB02Z) ranged from 0.4 to 8.3%, and admissions defined as “Intensive Care Advanced” (XB03Z) ranged from 4.9 to 12.3%. Admissions defined as “Intensive Care Basic Enhanced” (XB04Z) ranged from 18.7 to 51.5% in this group of units.

For PICUs with designated IC beds alone, the highest level of HRG provided was “Intensive Care Advanced Enhanced” (XB02Z) for 1.8%, ranging from 0.8 to 3.9%. Admissions defined
as “Intensive Care Advanced” (XB03Z) ranged from 2.3 to 5.4%, while those defined as “Intensive Care Basic Enhanced” (XB04Z) ranged from 5.4 to 18.9%.

For those PICUs with designated IC and HD beds, the highest level of HRG provided was also “Intensive Care Advanced Enhanced” (XB02Z) for 3.1%, ranging from 0.4 to 10.3%. Admissions defined as “Intensive Care Advanced” (XB03Z) ranged from 0.8 to 4.8%, and those defined as “Intensive Care Basic Enhanced” (XB04Z) ranged from 3.5 to 24.5%.

As expected, the proportion of admissions with their highest levels of care provision defined as “Intermediate Critical Care” (XB06Z), “Basic Critical Care” (XB07Z) or “Enhanced Care” (XB09Z) were in the PICUs with designated IC and HD beds: these comprised 51.8% of such admissions, ranging from 21.3% to 79.5%. For PICUs with IC designated beds alone, the proportion of admissions with their highest HRG as “High Dependency Advanced” or lower was 36.3% ranging from 23.2% to 53.1%, and for PICU ECMO units this proportion was 23.6% ranging from 11.2% to 46.1%.

Overall, there were significant differences both in the highest level of care provided during each admission and the proportion of days of care provided at each level, between the three groups of units.

Units defined as PICU / ECMO had significantly more admissions reaching higher levels of care, and as a proportion of their bed days (Figure 18). Intensive Care levels of care (XB01Z–XB05Z) were needed for at least 50% of admissions in all PICU / ECMO units, and in English units of this type it was close to 80% needing invasive ventilation. By contrast, the number of admissions not reaching any level of critical care was below 10% across this group, with bed days in each unit showing an almost identical pattern compared to the highest level of care provided during each admission.

For those four units defined as PICU only, the highest levels of care provided during admission and the proportion of bed days of care provided at each level, were again almost identical within each unit. However compared to the PICU / ECMO group, a greater percentage of admissions only reached Intermediate (XB06Z) or Basic (XB07Z) critical care levels or non-critical care (“Enhanced care” XB09Z) at between 20–50%, with the same pattern being seen in the proportion of bed days of care provided at each level.

For the PICU / HD units, there was a more variable picture, but the difference compared to the other two groups is still striking. For ten units, fewer than 50% of admissions reached Intensive Care levels of care (XB01Z–XB05Z), and fewer than 50% of bed days provided were at Intensive Care levels i.e. patients requiring invasive ventilation. There were considerable numbers of admissions who did not reach any level of critical care requirement (“Enhanced care” XB09Z), whilst the proportion of bed days at this level in many of these units exceeded 10% and in one unit was over 20%.

Example vignettes describing the care provision in each type of PICU are provided at the end of the chapter.
Figure 17: Proportion of admissions by Healthcare Resource Group and organisation 2016–2018

Proportion of admissions providing level of care

- HRG N/K
- EC
- HD
- HD-Adv
- IC-Bas
- IC-Enh
- IC-Adv
- IC-Adv-Enh
- IC-ECMO/ECLS

Proportion of admissions providing level of care
Figure 18: Proportion of days of care by Healthcare Resource Group and organisation 2016–2018

Variation in levels of care provision in designated PICUs from 2010 to 2018
Summary

This chapter has used a mixture of respiratory support information and HRG levels (Table 8) submitted to PICANet to investigate variations in PICU provision between units and to identify different unit types. Findings from this analysis have identified significant variations in levels of care provision by the three different types of PICU.

Changes in the care provided over time, along with changes in the designation of some units, either in terms of ECMO provision or the addition of High Dependency have been noted. Each unit is unique in terms of the services provided within its own hospital, and what, if any, critical care (High Dependency) provision exists outside the Paediatric Intensive Care Unit. At present, this provision remains unknown to PICANet as the focus has been on PICUs, but discussions concerning the potential inclusion of all critical care areas providing Level 2 care (i.e. intermediate Critical Care XB06Z) are currently taking place.

Overall there appear to be two separate and distinct changes taking place. For the most severely ill children, particularly those with cardiac diagnoses, a greater number are being supported with ECMO. This probably reflects a lower threshold for support for children following cardiac surgery, as its use has become more widespread across all cardiac surgical centres. However, the number of days on ECMO support has increased more than just the numbers might suggest, pointing to longer runs on ECMO. Whilst it may be that more complex post-surgical cases are now being supported on ECMO, requiring longer runs, it may also reflect a greater number of children with cardiac failure (e.g. cardiomyopathy) being supported for extended periods on ECMO whilst awaiting cardiac transplantation.

At the other end of the care range, for the PICU / HD units, the number of children admitted who do not require invasive ventilation has increased by 39.2% over time (8,884 in 2010–2012; 12,374 in 2016–2018), while the number of bed days of those never needing invasive ventilation has increased by 80% over the same period (16,225 in 2010–2012; 29,200 in 2016–2018), with the average length of stay increasing from 1.82 days to 2.36 days. Some of this may reflect a greater use of non-invasive support for certain patient groups, including for example those with chronic complex conditions for whom invasive ventilation may not be appropriate, especially as the number of non-invasive ventilation days increased across all units during this time, or it could reflect changes of practice within individual hospitals as units become more clearly PICU / HD units.

A considerable proportion of patients in the PICU / HD units never reach the HRG-defined levels of critical care during their PICU admission. More work needs to be undertaken to understand this group, and the reasons for admission, especially as almost all units have some of these patients, and in total they constitute a substantial number of PICU bed days. Given the pressure on PICU bed availability during the winter period, as respiratory admissions increase, the effect of seasonality also needs to be considered. Vignettes providing examples of children admitted to the types of PICU are provided

As more work is undertaken to review these figures, they should be used by commissioners and clinical leads in the development of the Operational Delivery Networks and to inform the development of critical care provision across England, the devolved nations of the United Kingdom and the Republic of Ireland.
Vignettes

PICU / ECMO

Child A was an unplanned admission to PICU / ECMO on the day of birth, transferred from a Neonatal Intensive Care Unit in another hospital.

Primary diagnosis: Total anomalous pulmonary venous drainage
Surgical procedure: Repair of total anomalous pulmonary venous drainage

The child received ECMO from day 0 to day 6 and invasive ventilation via an endotracheal tube from day 0 to day 8. On day 8 the baby was extubated to supplementary oxygen and discharged to a ward in the same hospital.

PICU

Child B aged 13 years was a planned admission to PICU from theatre and recovery following surgery.

Primary diagnosis: Subglottic stenosis
Surgical procedure: Reconstruction of larynx

The child was intubated and ventilated on admission from theatre. Invasive ventilation was maintained until day 4, when the child was extubated to air, and then discharged home directly from PICU (i.e. to “normal residence”) on the following day.

PICU / HD

Child C aged two months was an unplanned admission to PICU / HD from a ward in the same hospital.

Primary diagnosis: Obstructive sleep apnoea and craniosynostosis

The child received non-invasive ventilation from day 0 to day 11 and was then discharged to a ward in another hospital for continuing non-invasive ventilation.

With thanks to Peter Davis (PICANet CAG Chair) for his clinical input into this chapter.
References


4. Paediatric Critical Care and Surgery in Children Review

Additional information

Background

PICANet was established in 2001 with funding from the Department of Health and started collecting data from English and Welsh paediatric intensive care units in November 2002. The PICUs at the Royal Hospital for Sick Children, Edinburgh and the Royal Hospital for Children, Glasgow started submitting data in December 2004 and March 2007 respectively. The Royal Belfast Hospital for Sick Children joined in April 2008 and Children's Health, Ireland, Crumlin and Children's Health, Ireland, Temple Street, both based in Dublin, have submitted anonymised data to PICANet since 2009 and 2010, respectively. The Harley Street Clinic PICU started contributing data in September 2010, and the PICU at the Portland Hospital from October 2013, allowing both these non-NHS units to compare their performance against the national benchmark provided by PICANet.

A full list of participating PICUs can be found in Appendix A.

Governance

PICANet continues to receive support from the NHS Health Research Authority Confidentiality Advisory Group (NHS HRA CAG) (formerly the NIGB) to collect personally identifiable data without consent on infants and children admitted to paediatric intensive care.

See https://www.hra.nhs.uk/documents/1778/piag-register-master-08082019-SD_grWbiR.xls

Ethics approval has been granted by the Trent Medical Research Ethics Committee, ref. 18/EM/0267.

PICANet supports transparency in its data processing and has patient information sheets and posters on display in PICUs and issues a Privacy Notice and Fair Processing Statement on its website outlining the legal basis for processing of data under the General Data Protection Regulations (May 2018). Details can be found at https://www.picanet.org.uk/.

PICANet receives support and advice from a Clinical Advisory Group (CAG) drawing on the expertise of doctors and nurses working within the speciality and a Steering Group (SG), whose membership includes Health Services Researchers, representatives from the Royal Colleges of Paediatrics and Child Health, Nursing and Anaesthetics, a lay member and commissioners. Appendices B and C provide a full list of CAG and SG members. Additional support from the clinical community is provided through the UK Paediatric Intensive Care Society.

Commissioning

The following organisations commission paediatric intensive care in the UK:

- England: NHS England Specialised Services
- Wales: Specialist Health Service Commission for Wales (SHSCW)
- Scotland: National Services Division of NHS National Services Scotland
- Northern Ireland: Health and Social Care Board

In the Republic of Ireland, Children’s Health Ireland, Crumlin and Children’s Health Ireland, Temple Street are both voluntary hospitals, funded by the Health Service Executive.
Methods

Basic methodology

Most critically ill children who need complex clinical care and life support are treated in Paediatric Intensive Care Units (PICUs). These children may have had complex surgery, an accident or a severe infection and may arrive in the PICU from an operating theatre, emergency department or from a hospital ward. In some cases they may have been transferred from another hospital and, rarely, admitted directly from home.

PICANet is an audit that collects personal, organisational and clinical data on all children with a clinically determined need for paediatric intensive care in the UK and Ireland, to compare outcomes and activity between PICUs and specialist transport organisations and also between health regions and nations.

Data are stored on a secure database. Each organisation is able to view and download their own data and reports on their data quality and activity as well as comparative national data. An annual report is produced each autumn that includes a summary of what has happened to children admitted to PICU including why they were admitted, where they were admitted from, how long they stayed, what treatments they received and their outcome at the time of discharge. Comparisons between PICUs are made to assess how well they perform against established clinical standards and guidelines.

In addition to the annual report, PICANet provides technical and statistical support for the use of its data for local audit and research, regional and national commissioning, national and international research and to provide baseline information for clinical intervention trials.

Participating organisations and data submission

PICANet has collected data from all PICUs in England and Wales since 2002. The two PICUs in Scotland, one from Northern Ireland and two from the Republic of Ireland, along with two non-NHS units based in London have joined PICANet at different times so that coverage is now for the whole of the UK and the Republic of Ireland. There are 32 PICUs and 12 specialist transport organisations currently submitting data to PICANet.

Data are submitted by individual PICUs prospectively, using our secure web-based data collection application with real-time online validation reporting, systematic monthly validation review by our research nurse and regular on-site validation visits. Data submission can involve direct entry of patient data or an upload of a data file from an existing clinical information system. PICANet provides full documentation on data definitions, which have been developed in collaboration with our Clinical Advisory Group, as well as technical specifications for IT and database professionals. In addition, standardised data collection forms are supplied to all organisations where there is no in-house provision for data collection.

Data collected

PICANet collects three core datasets:

**Admission data** contains demographic details of each child including their name*, date of birth**, NHS/CHI number, address* and ethnic group; it also records where children are admitted from, their date of admission and clinical diagnoses, some physiological parameters on admission including blood gases, blood pressure, medical history and ventilation status. Data on outcome and discharge details are included. The medical interventions received on each day by each child are recorded as part of the audit and to help NHS organisations in England to supply information on the cost of their activity.
Referral data for all children where clinicians agree a paediatric intensive care bed and/or paediatric intensive care transport is required includes details of the referring hospital, demographic details of the child, grade of the referring doctor or nurse, the outcome of the referral, the transport team involved and the destination PICU.

Transport data for all children transported to a PICU from their original admitting hospital or who are transported by a specialist PIC transport service but are not admitted to a PICU includes patient details as well as information about their presenting physiology. Details of the composition of the transport team, journey times, any interventions carried out and critical incidents are also recorded.

Additional data collection takes place to understand more about staffing on PICU:

Staffing data are collected each year in November to monitor staffing levels within PICUs as well as the PICS standards relating to staffing requirements.

* Not collected for data from Northern Ireland or the Republic of Ireland

** Limited to month and year for Northern Ireland

Analytical techniques

Statistical techniques used include simple cross tabulations, the calculation of crude and risk-adjusted SMRs and 95% confidence intervals; the construction of crude and risk-adjusted funnel plots of SMRs; and local provision of Risk Adjusted Resetting Sequential Probability Ratio Test (RA-RSPRT) plots to assess real-time performance related to in-PICU mortality. Risk adjusted SMRs were calculated using the latest version of the Paediatric Index of Mortality, PIM³ recalibrated based on data within the current reporting period.

Assessing case ascertainment, data quality and validation

PICANet Web allows PICU staff to obtain reports on their own data to check monthly admissions totals. In addition, during validation visits by the PICANet research nurse a cross check is carried out against records held on PICU (such as admission books, or in-house data collection systems) and PICANet Web. These checks allow us to assess case ascertainment and the on-site validation visits are a core element of our data quality assurance process.

Data are validated online via PICANet Web using logic and range checks as well as flagging missing data items. The Modulus 11 algorithm is used to validate the NHS number based on a check digit – this is a standard method of ensuring the NHS number is a true NHS number and improves our ability to trace patients through the PICANet database and in linked healthcare data.

Collaborative working supporting policy, commissioning, research and clinical trials

PICANet has become established as the definitive source of data on paediatric intensive care activity in the UK and Ireland. Its data have been used to plan PIC services, model demand, assess interventions and outcomes and provide data to underpin research to facilitate the development of new standards for critical care provision for children. PICANet has provided baseline data for the development of the I-KID, SANDWICH and FEVER trials, all of which have been funded and will make use of the routinely collected PICANet data using the custom data download facility. This allows local control over the data. We are also working closely with a number of other funded studies, including DEPICT, ENACT, FIRST-ABC, LAUNCHES-QI, Neuro-PACK, OXY-PICU, PERMIT, PREVAIL and QualDash.
Small number policy

Publication of PICANet data is subject to scrutiny of small numbers. When small numbers of admissions are involved, other data items may become identifiable i.e. a living individual may be identified from the data. This is still the case in aggregated data where small groups of individuals are presented. These are reviewed and in some cases, categories are combined or cells anonymised where necessary.

Outlier policy

When unusual performance is detected following routine or bespoke analysis, which suggests that a PICU is an outlier, PICANet follow the established procedure outlined in our outlier policy, which relates specifically to assessment of risk-adjusted mortality.

Historically there have been three specific occasions where PICUs have been identified as outliers with excess risk-adjusted mortality. In two of these cases this was attributable to data quality issues and when corrected, the outliers fell within normal limits. In one case this was not attributable to data quality and resulted in internal and external reviews.


Links with the clinical community, patients and their families

PICANet has until recently had an active PICU Families Group comprising both Lay representatives (parents of children who are currently or have previously received paediatric intensive care) and a multidisciplinary group of health professionals including Family Liaison Sisters, critical care nurses, audit staff, PIC consultants and members of the PICANet team. Availability of Lay representatives has become difficult over recent years and so we are developing a Lay stakeholder group encompassing any PIC or disease specific support group that deals with parent or child PIC related issues to feed into the future development of PICANet. In addition, we have a standing lay representative on our Steering Group and work closely with the charity Well Child. To date, all communications we have had from patients/parents have been very positive, supporting PICANet and its work and requesting further information.

PICANet has the support of the Paediatric Intensive Care Society and the associated PICS Study Group, the PICANet Clinical Advisory Group and the Clinical Reference group which oversees Paediatric Critical Care and PCC transport.
<table>
<thead>
<tr>
<th>Glossary</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAG</td>
</tr>
<tr>
<td>CCG</td>
</tr>
<tr>
<td>CHI</td>
</tr>
<tr>
<td>CTS</td>
</tr>
<tr>
<td>EC</td>
</tr>
<tr>
<td>ECLS</td>
</tr>
<tr>
<td>ECMO</td>
</tr>
<tr>
<td>GDPR</td>
</tr>
<tr>
<td>HD</td>
</tr>
<tr>
<td>HD-Adv</td>
</tr>
<tr>
<td>HFNCT</td>
</tr>
<tr>
<td>HQIP</td>
</tr>
<tr>
<td>HRA</td>
</tr>
<tr>
<td>HRG</td>
</tr>
<tr>
<td>IC</td>
</tr>
<tr>
<td>IC-Adv</td>
</tr>
<tr>
<td>IC-Adv-Enh</td>
</tr>
<tr>
<td>IC-Bas</td>
</tr>
<tr>
<td>IC-ECMO/ECLS</td>
</tr>
<tr>
<td>IC-Enh</td>
</tr>
<tr>
<td>NCAPOP</td>
</tr>
<tr>
<td>NHS</td>
</tr>
<tr>
<td>NOCA</td>
</tr>
<tr>
<td>PIC</td>
</tr>
<tr>
<td>PICANet</td>
</tr>
<tr>
<td>PICS</td>
</tr>
<tr>
<td>PICU</td>
</tr>
<tr>
<td>PIM3</td>
</tr>
<tr>
<td>RA-RSPRT</td>
</tr>
<tr>
<td>ROI</td>
</tr>
<tr>
<td>SG</td>
</tr>
<tr>
<td>SHSCW</td>
</tr>
<tr>
<td>SMR</td>
</tr>
<tr>
<td>UK</td>
</tr>
<tr>
<td>WTE</td>
</tr>
</tbody>
</table>

**CAG** Clinical Advisory Group  
**CCG** Clinical Commissioning Group  
**CHI** Community Health Index  
**CTS** Central Transport Services  
**EC** Enhanced care  
**ECLS** Extracorporeal life support  
**ECMO** Extracorporeal membrane oxygenation  
**GDPR** General Data Protection Regulation  
**HD** High dependency  
**HD-Adv** High dependency advanced  
**HFNCT** High flow nasal cannula therapy  
**HQIP** Healthcare Quality Improvement Partnership  
**HRA** Health Research Authority  
**HRG** Healthcare Resource Group  
**IC** Intensive Care  
**IC-Adv** Intensive care advanced  
**IC-Adv-Enh** Intensive care advanced enhanced  
**IC-Bas** Intensive care basic  
**IC-ECMO/ECLS** Intensive care extracorporeal membrane oxygenation/extracorporeal life support  
**IC-Enh** Intensive care basic enhanced  
**NCAPOP** National Clinical Audit and Patient Outcomes Programme  
**NHS** National Health Service  
**NOCA** National Office of Clinical Audit  
**PIC** Paediatric Intensive Care  
**PICANet** Paediatric Intensive Care Audit  
**PICS** Paediatric Intensive Care Society  
**PICU** Paediatric Intensive Care Unit  
**PIM3** Paediatric Index of Mortality 3  
**RA-RSPRT** Risk Adjusted Resetting Sequential Probability Ratio Test  
**ROI** Republic of Ireland  
**SG** Steering Group  
**SHSCW** Specialist Health Service Commission for Wales  
**SMR** Standardised mortality ratio  
**UK** United Kingdom  
**WTE** Whole time equivalent
University of Leeds

Richard Feltbower
Hannah Buckley
Sophie Butler
Victoria Hiley
Lee Norman

PICANet
School of Medicine
University of Leeds
Clarendon Way
Leeds
LS2 9JT

University of Leicester

Elizabeth Draper
Tracy Harris
Caroline Lamming
Lyn Palmer
Martin Perkins
Sarah Seaton

PICANet
Department of Health Sciences
University of Leicester
George Davies Centre
University Road
Leicester
LE1 7RH