







Paediatric Intensive Care Audit Network



Annual Report 2017

Data collection period January 2014 – December 2016



UNIVERSITY OF LEEDS



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Summary Report

| ΚΕΥ | | |
|----------|---|--|
| A | Cambridge, Addenbrooke's Hospital | |
| B* | Brighton, Royal Alexandra Hospital | |
| С | Cardiff, Noah's Ark Children's Hospital for Wales | |
| D | Manchester, Royal Children's Hospital | |
| E1 | London, Great Ormond Street Hospital - PICU/NICU | |
| E2 | London, Great Ormond Street Hospital - CICU | |
| F | London, Evelina Children's Hospital | |
| G | Hull Royal Infirmary | |
| Н | London, Kings College Hospital | |
| I | Leeds General Infirmary | |
| КЗ | Newcastle, Great North Children's Hospital | |
| К2 | Newcastle Freeman Hospital | |
| L | Stoke on Trent, Royal Stoke University Hospital. | |
| Μ | Nottingham, Queen's Medical Centre | |
| N | Oxford, John Radcliffe Hospital | |
| 0 | London, Royal Brompton Hospital | |
| Р | Liverpool, Alder Hey | |
| Q | Sheffield Children's Hospital (PICU) | |
| R | Southampton Children's Hospital | |
| S | Middlesbrough, James Cook Hospital | |
| Т | London, St George's Hospital | |
| U | London, St Mary's Hospital | |
| V | Birmingham Children's Hospital | |
| W | Bristol, Royal Hospital for Children | |
| X | Leicester Glenfield Hospital | |
| X | Leicester Royal Infirmary | |
| Y Z | Edinburgh Royal Hospital for Sick Children | |
| 2 | London, The Royal London Hospital | |
| | Glasgow Royal Hospital for Children | |
| 2B 7C | Bellast, Royal Bellast Hospital for Sick Children | |
| 2C 7D | Dublin, Our Lauy's Children's Hospital Tomple Street | |
| 75 | London, Harloy Stroot Clinic | |
| 2L 7E | London, The Portland Hospital | |
| T001 | CATS - Children's Acute Transport Service | |
| T002 | Embrace: Vorkshire & Humber Infant & Children's Service | |
| T003 | NWTS: North West and North Wales P T S | |
| T004 | STRS - South Thames Retrieval Service | |
| T005 | KIDS Intensive Care & Decision Support | |
| T008 | SORT - Southampton, Oxford retrieval team | |
| T010 | NISTAR - Paediatric | |
| T016 | SCOTSTAR – Edinburgh team | |
| Т020 | SCOTSTAR - Paediatric Retrieval Service | |
| T022 | IPATS - Irish Paediatric Acute Transport Service | |
| T024 | WATCh - Wales and West Acute Transport for Children | |
| Т026 | NECTAR - North East Children's Transport and Retrieval | |

* Brighton ceased to be a designated PICU in 2014 and Hull Royal Infirmary ceased to be a designated PICU in 2013 submitting data upto 2017, so will not be included in future annual reports

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ISBN: 978 0 85316 353 4

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ACKNOWLEDGEMENTS

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).

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.

We are also grateful for the support and commitment given by members of the PIC Families Group.

The PICANet Audit is funded by the Healthcare Quality Improvement Partnership (HQIP), the Welsh Government, NHS Lothian/National Service Division NHS Scotland, the Royal Belfast Hospital for Sick Children, The National Office of Clinical Audit (NOCA), Republic of Ireland and HCA Healthcare. The Healthcare Quality Improvement Partnership (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 National Clinical Audit and Patient Outcomes Programme (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 dependencies. and crown www.hqip.org.uk/national-programmes.

FOREWORD

This is the fourteenth annual report produced by PICANet. Each year we have produced a report in a slightly different format. This year, the Summary Report has been simplified to make it more accessible for all potential readers. As well as summarising some of the main figures from the audit we focus on five quality measures that have been selected to answer three of the five Care Quality Commission Key Questions relating to Responsiveness, Safety and Efficacy in the Paediatric Intensive Care Service. We present these data overall for the UK and Republic of Ireland and by individual country.

PICANet reports a number of metrics, some of which have been adopted by the CQC and also appear in the PIC quality dashboard, but there is little evidence as to how the standards have been developed. For example, there is no acceptable level set for unplanned extubation and so we have made comparisons against the average for the whole audit. The same case applies to emergency readmissions within 48 hours. It may be that any final standard needs to be agreed by consensus and PICANet is providing the baseline data that will help that consensus be achieved.

We have also looked at survival after discharge from PICU using death certificate data from NHS Digital for English children only.

This makes the summary report much shorter, but the large body of data that we produce each year in the tables and figures are still available. These are highly valued by clinical colleagues and commissioners as a source of high quality information on paediatric intensive care activity in the UK and the Republic of Ireland. The summary report and main tables and figures provide a wealth of information to enable quality improvement at a local and national level, particularly in relation to commissioning services and identifying pressures on the paediatric intensive care service.

In the past year PICANet has participated in the Paediatric Critical Care Review sponsored by NHS England both by providing data to inform the work of the Review and as part of the Expert Stakeholder Panel. If the Review recommends changes to the way paediatric intensive care is delivered in England, PICANet will be able to measure what impact those changes have on activity and quality of care.

Roger Parslow Liz Draper Principal Investigators

EXECUTIVE SUMMARY

- There were just over 20,000 admissions to paediatric intensive care in the UK and the Republic of Ireland per year in the period 2014-2016, a small increase on 2013-2015. The PICU in Wales had a 79% increase between 2014 and 2016 following the co-location of the paediatric intensive care unit and the high dependency unit in one critical care facility in February 2015.
- The number of bed days delivered increased by over 4% over the reporting period from 135,359 in 2014 to 141,150 in 2016 for the UK and the Republic of Ireland. Bed days in the PICU in Wales increased over twofold during this three year period (109%) with the additional reporting of high dependency patients from the newly co-located critical care unit
- There is wide variation in the rate of admission for paediatric intensive care between the countries of the UK and the Republic of Ireland ranging from 146 admissions per 100,000 children in England to 194 admissions per 100,000 children in Northern Ireland.
- Crude mortality rates in PICUs are very low (less than 4%). The steady trend in the reduction of these rates has continued over the reporting period from 3.8% in 2014 to 3.4% in 2016.
- Unplanned extubation rates in PICU are very low, ranging from 1 to 6 per 1000 days of invasive ventilation between the countries of the UK and the Republic of Ireland. To date there are no standards for what is an acceptable rate of unplanned extubation (an adverse event that may be associated with clinical complications).
- Use of agency & bank nursing staff on PICUs is rare in most areas of the UK & Republic of Ireland during normal working hours except in NHS hospitals in London where 15% of the nursing staff working on census Wednesday in November 2016 were bank or agency employees. This increased to over one fifth (22%) of nursing staff 'out of hours' on census Sunday at midday in London.
- Reported rates of occupancy in PICUs were very high during the staffing census week with occupancy rates of 95% in England and 100% in Wales for intensive care beds during normal working hours. These rates showed little reduction 'out of hours' across the UK and the Republic of Ireland.

- In 2015-2016, 7 out of 10 paediatric critical care transports were mobilised within one hour following the agreement by clinicians that a child needed urgent critical care.
- In 2016 just over half (55%) of PICUs met the recommended nurse to patient ratio during normal working hours (midday census Wednesday). This was a reduction from 2015 when two thirds (67%) of PICUs met this standard at the census.
- Around 2% of children admitted to PICUs are discharged and then readmitted as an emergency within 48 hours. Emergency readmission is regarded as an adverse event affecting the child, carers and admitting unit.
- Twelve per cent of English children who were admitted to a PICU during the period 2002 – 2015 have died either in PICU or following discharge. This increases to 19% (nearly 1 in 5 children) of south Asian ancestry.

RECOMMENDATIONS

- 1. PICANet should work with the Paediatric Intensive Care Society, the Care Quality Commission and other stakeholders to develop an evidence-base for standards and quality metrics reported by PICANet.
- 2. PICANet should continue providing data and analytical support to the National Review of Paediatric Critical Care who should work jointly with the Paediatric Intensive Care Society to establish evidence-based standards for staffing numbers. Guidance on staffing levels should form part of the Review recommendations.
- 3. In the following year PICANet should work with PICUs and the Paediatric Intensive Care Society to assess the impact of bed occupancy level and staffing ratios on PICANet outcome measures, particularly unplanned extubation, emergency readmission and mortality rates at times of high occupancy and staff shortages.
- 4. Over the next year PICANet should work with the PICS Acute Transport Group to develop an effective means of reporting and assessing the causes of delay in mobilising paediatric intensive care transport teams, providing feedback that will allow the teams to make decisions about how to improve their performance.
- 5. The NHS should prioritise the commissioning of research that investigates the high levels of mortality in South Asian children in the general population which persist in those admitted for paediatric intensive care.

KEY RESULTS

In this year's summary report we describe our findings for the five quality metrics adopted by the Care Quality Commission (case ascertainment, mobilisation time, nurse establishment, emergency readmissions and SMR), identified in collaboration with the Care Quality Commission (CQC) and selected to answer three of the five CQC Key Questions relating to Responsiveness, Safety and Efficacy in the Paediatric Intensive Care Service.

Firstly, we present some headline figures from the main report to give the reader an understanding about the numbers of children admitted to PICUs, and what happens to them, as well as details of our snapshot survey of staffing carried out each year. Where it is possible, we have broken down the results by country in which the PICUs are based. This allows a comparison between countries in the UK and the Republic of Ireland.

The results presented are presented in a new format with a short explanation about what we have done, what we found and what this means. On the back of each page with the explanatory boxes we give a short but more detailed description of what we did and provide some interpretation in relation to the importance of the findings.

There is also a preliminary report on survival after PICU discharge for English children.

As in previous years, the PICANet annual report comprises three sections and this summary report should be read in conjunction with the Tables and Figures and the Appendices for additional information and a detailed breakdown.

HOW WE PRESENT OUR RESULTS

Results are presented in tables and figures and maps. We use what are called 'funnel plots' to compare individual PICUs with the overall average for the United Kingdom and the Republic of Ireland for some of the things we measure: these include mortality, emergency readmissions and unplanned extubation. Each of these measures is explained at the top of the page which displays the results. Here we describe below how funnel plots should be read.



FIGURE 1: EXAMPLE FUNNEL PLOT

Figure 1 is a simple diagram 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, given that there are normal 'ups and downs' (natural variation). The limits are wider where there are fewer admissions because with only a few values we cannot be as certain about our findings. With more values we can be more confident that the outcome is likely to fall within narrower limits. This is the same principle as tossing a coin: if you tossed it only 10 times you might get 9 heads and 1 tail, just by chance. If you tossed it a 1000 times you are much more likely to have about half heads and half tails.

The blue dots represent the PICUs with different numbers of admissions. The red dot indicates a PICU that is outside the upper limit. We say that this is 'statistical outlier' and we have a process for investigating why this has occurred.

The blue line in the middle of the funnel represents the average that is expected based on the United Kingdom and the Republic of Ireland findings as a whole. You would always expect a scatter of dots above and below this line if you know the average. The whole point about funnel plots is to allow us to see differences between units taking into account what might be natural variation.

The tables below tell you how many admissions there were to paediatric intensive care units in the UK and Republic of Ireland for children aged under 16 years and how many days of paediatric intensive care were delivered in 2014, 2015 and 2016. Each day a child stays on a PICU is called a 'bed-day'.

What did we find?

Table 1 shows there are around 20,000 admissions per year and this number has increased slightly over the 3 years, mainly in PICUs in England and Wales. The 79% increase in Wales is due to the creation of a co-located PICU and high dependency unit. There is a similar increase in the number of bed days delivered (Table 2).

| Country | | 2014 | 2015 | 2016 |
|--------------------------|----------------|---------------|---------------|---------------|
| UK & Republic of Ireland | | 19,779 | 19,983 | 20,320 |
| England | NHS Non-NHS | 15,602 423 | 15,897 270 | 16,016 329 |
| Wales | | 296 | 466 | 530 |
| Scotland | | 1,458 | 1,322 | 1,487 |
| Northern Ireland | | 507 | 630 | 557 |
| Republic of Ireland | | 1,493 | 1,398 | 1,401 |

TABLE 1: NUMBER OF ADMISSIONS, BY COUNTRY, BY YEAR

TABLE 2: NUMBER OF BED DAYS DELIVERED, BY COUNTRY, BY YEAR

| Country | | 2014 | 2015 | 2016 |
|--------------------------|----------------|------------------|------------------|-----------------|
| UK & Republic of Ireland | | 135,359 | 136,796 | 141,150 |
| England | NHS Non-NHS | 105,460 4,361 | 109,293 2,444 | 110456 3,318 |
| Wales | | 1,366 | 2,380 | 2,859 |
| Scotland | | 9,602 | 8,763 | 10,641 |
| Northern Ireland | | 3,712 | 3,795 | 3,535 |
| Republic of Ireland | | 10,858 | 10,121 | 10,341 |

What does this mean?

The need for paediatric intensive care is rising very slightly, reflected by increases in admissions & bed days delivered in England & Wales. This may be due to a small increase in births in 2015 although births in 2016 have decreased in England & Wales.

Definitions and methods

Every admission to a PICU in the UK and the Republic of Ireland is counted for each year, 2014-2016. If a child has been readmitted during that period this will also be counted. A 'bed day' is counted if a child is in a PICU bed for a day or part of a day. We have only given 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.

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 is being considered by the current Paediatric Critical Care Review for England.

Figure 2 below shows how many children per 100,000 childhood population were admitted to PICU by country. This measures what proportion of the childhood population are admitted to paediatric intensive care each year.

What did we find?

The overall rate of admissions for the UK and Republic of Ireland is about 150 admissions for every 100,000 children. This varies from 194 per 100,000 in Northern Ireland to 146 per 100.000 in England

FIGURE 2: RATE OF ADMISSIONS PER 100,000 CHILDHOOD POPULATION



What does this mean?

Admissions rates vary by country. This is probably related to a number of things, including the distance to a PICU, the admissions policy in different countries (some PICUs may accept children who need a lower level of intensive care so would have more admissions) and what other healthcare is available for critically ill children.

Definitions and methods

Having counted the admission numbers, we have then worked out how many admissions there are for every 100,000 children under 16 in each of the UK countries and the Republic of Ireland. This is called the admission rate. We have used national census data to find out what the childhood population is in each country.

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.

We record all deaths prior to discharge from PICU and report them here for children under 16 for the years 2014-2016.

What did we find?

Table 3 gives the number of deaths in PICU by country by year. For the UK and Republic of Ireland there were 2196 deaths over the three years. This means that over 96 out of every hundred children admitted to PICU are discharged alive.

| Country | 2014 | 2015 | 2016 |
|--------------------------|-------------------------|-------------------------|-------------------------|
| UK & Republic of Ireland | 742 (3.75%) | 762 (3.81%) | 692 (3.41%) |
| England NHS Non-NHS | 589 (3.71%) 6 (1.4%) | 627 (3.91%) 5 (1.9%) | 574 (3.57%) 9 (2.8%) |
| Wales | 16 (5.41%) | 8 (1.72%) | 11 (2.08%) |
| Scotland | 28 (1.92%) | 30 (2.27%) | 36 (2.42%) |
| Northern Ireland | 21 (4.14%) | 20 (3.17%) | 9 (1.62%) |
| Republic of Ireland | 82 (5.49%) | 72 (5.15%) | 53 (3.78%) |

TABLE 3: NUMBER OF DEATHS IN PICU, BY COUNTRY, BY YEAR

What does this mean?

Death in paediatric intensive care is not common and has reduced since 2003-2004 when the rate was 5.5%.

Definitions and methods

We have recorded the number of deaths by year by country. The percentages we have given are based on the number of admissions, not the number of children.

Why is this important?

Death on PICU is rare and the percentage of deaths has reduced since PICANet started collecting data: it is important to record these numbers to detect these trends over time. It also highlights differences between countries although where there are very small numbers of deaths we should be very cautious about making comparisons as apparently large differences may happen by chance.

Children who need help with their breathing may have a tube down their throat connected to a machine: this is called invasive ventilation. If the tube comes out accidentally, this is called 'unplanned extubation'. Here we measure the number of unplanned extubations for every thousand days of invasive ventilation.

What did we find?

In 2016 there were only 259 unplanned extubations out of over 69,000 days of invasive ventilation in the UK & Republic of Ireland, giving a rate of 4 unplanned extubations for every 1000 days of invasive ventilation. Figure 3 shows that PICU ZA had higher rates of unplanned extubation when compared with all other units.

| Country | 2015 Number | 2015 rate | 2016 Number | 2016 rate |
|--------------------------|----------------|--------------|----------------|--------------|
| UK & Republic of Ireland | 295 | 5 | 259 | 4 |
| England NHS Non NHS | 214 0 | 4 0 | 181 1 | 3 2 |
| Wales | <5 | 2 | <5 | 3 |
| Scotland | 40 | 1 | 35 | 8 |
| Northern Ireland | 5 | 3 | <5 | 1 |
| Republic of Ireland | 33 | 6 | 36 | 6 |

TABLE 4: UNPLANNED EXTUBATIONS PER 1000 DAYS INVASIVE VENITLATION

FIGURE 3: UNPLANNED EXTUBATION RATIOS BY HEALTH ORGANISATION



What does this mean?

While every effort is made to prevent accidental extubation, some patients may have complex clinical conditions that make it more likely. There is no set standard for what is an acceptable rate so we have compared PICUs against the overall average for the UK and Republic of Ireland.

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 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 1000 invasive ventilation days delivered. That makes comparisons between units with different volumes of invasive ventilation possible. Unplanned extubation is referred to as an 'adverse event'.

Why is this important?

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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, death¹. 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 agreed². Kanthimathinathan and colleagues do refer to a notional threshold of 1/100 invasive ventilation days which is 10/1000 days¹. In this context, even PICU ZA have good performance despite being outside the control limits of the funnel plot. By continuously monitoring unplanned extubation rates it may be possible to detect when a change in practice (such as the change in the Elastoplast tapes that caused an increase in unplanned extubation rates noted by Kanthimathinathan and colleagues)¹.

¹ Kanthimathinathan et al (2015). Unplanned extubation in a paediatric intensive care unit: prospective cohort study. Intensive Care Med (2015) 41:1299-1306. DOI 10.1007/s00134-

² NHS England 2015. <u>https://www.england.nhs.uk/commissioning/wp-</u> content/uploads/sites/12/2015/01/e07-sa-paed-inten-care.pdf

If a child needs urgent admission to a PICU, a referral is made to the specialist critical care transport team or PICU transport team. Sometimes the initial referral may not result in a transport and this is called a refusal. We have recorded the number of successful and refused transports and the reasons why they are refused

What did we find?

We recorded details of nearly 15,000 referrals for urgent admission to PICU, three quarters (11,521) were transported. Just over 1 in 5 (3,399) of initial referrals did not result in the child being transported to PICU. Of these, about two thirds (2,182) were refused because no staffed bed was available.



FIGURE 4: REASON TRANSPORT NOT UNDERTAKEN FOLLOWING REFERRAL FOR URGENT ADMISSION TO PAEDIATRIC INTENSIVE CARE

What does this mean?

When a transport team receives a referral and agree to transport a child they check whether there are any beds available. Two-thirds of the referrals that did not result in a transport were refused due to no staffed bed. This means the child may have to wait and have more than one referral before being transported.

Definitions and methods

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

Why is this important?

In just under a third of cases where the child was not transported, a PICU bed was not requested in the end, and there are many different reasons for this but we do not record the details. Around two thirds of the refusals were due to no staffed bed being available, an indication of how busy the service is at that time. When this happens, the transport services continue to search for an available PICU bed, perhaps in another part of the country. This may result in a delay in the child receiving intensive care.

Delays in receiving intensive care may have clinical implications and can cause stress for the patients and their carers. In December 2016 there was a similar situation with refusals and Dr Peter-Marc Fortune, chair of the Paediatric Intensive Care Society told the Guardian newspaper that in the previous two weeks he was aware of a child having to be transported 120 miles to an intensive care bed, and a second case in which an acutely ill child had to wait nine hours before a free bed could be identified.

Dr Fortune is quoted as saying: "There are therapies that require a child to be physically in an intensive care unit. If there were an occasion when such therapies were required, with no beds immediately available, we could be forced into a triage situation where other children may have to wait or be moved between beds."³

Dr Fortune's comments clearly explain the possible issues that arise if an urgent transport request is refused.

³ <u>https://www.theguardian.com/society/2016/dec/10/acutely-ill-children-waiting-nine-hours-for-beds-nhs-paediatricians</u>

The proportion of qualified nursing staff from a bank or agency on duty in PICUs during 'normal hours': Wednesday at midday in November 2014, 2015 & 2016 for the UK countries and the Republic of Ireland

What did we find?

The largest proportion of bank & agency nursing staff use during 'normal hours' is in London PICUs: 15% midday Wednesday. In PICUs in the rest of England & in Scotland bank and agency staff make up around 5% of qualified nursing staff. No bank & agency staff were used in Wales, Northern Ireland & Republic of Ireland.



FIGURE 5: PERCENTAGE OF BANK & AGENCY NURSING STAFF WORKING ON PICU MIDDAY WEDNESDAY, NOVEMBER 2014-2016

What does this mean?

During 'normal hours' (represented by midday Wednesday) the main use of bank and agency nursing staff is in the London PICUs where they comprise over one eighth of the workforce. This may reflect the large demand for staff in London where around one third of English PICUs are located.

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 III Children (5th Edition, December 2015). Staffing data is collected in the November of each year. Figure 5 compares the findings from 2016 with the two previous years: 2014 and 2015.

In 2016, questionnaires were sent to the lead doctor and senior nurse in each PICU. Information was collected on the medical and nurse establishment for each PICU, including details of any vacant posts due to illness, maternity leave or if posts are unfilled during the week beginning 21st November.

Details were collected about the number of staff working at four 'snapshot' time periods: a weekday and weekend at noon and midnight, including the use of any bank and agency nursing staff. For the purposes of calculating the 'normal hours', use of bank and agency nursing staff data were analysed for the data from Wednesday at noon (Figure 5). 'Out of hours' use of bank and agency staff was calculated using the data from Wednesday at midnight, Sunday at midday and Sunday at midnight. In Figure 6 we present the data for midday on Sunday.

Why is this important?

PICUs need to be able to monitor whether they have adequate nursing staff available to run their unit efficiently. Use of bank and agency staff highlights problems with current staffing levels which may be due to staff illness or problems with staff retention. The efficiency of the unit may also be compromised in terms of team working and a lack of continuity of care. In addition, these staff may have limited knowledge about unit policies, working practices and equipment and may not be able to administer medication until they have been assessed as competent. Their use also adds an additional financial burden to their hospital.

The proportion of qualified nursing staff from a bank or agency on duty 'out of hours' in PICUs on a Sunday at midday in November 2014, 2015 & 2016 for the UK countries and the Republic of Ireland.

What did we find?

The largest proportion of bank and agency nursing staff use on a Sunday at midday is in London PICUs, 22%. On the 'out of hours' time period midday Sunday there was also an increased use of bank and agency staff (14%) in Scotland and Northern Ireland in 2016.



FIGURE 6: PERCENTAGE OF BANK & AGENCY NURSING STAFF WORKING ON PICU AT MIDDAY SUNDAY, NOVEMBER 2014-2016

What does this mean?

Use of bank and agency nursing staff 'out of hours' occurs mainly in the London PICUs where they comprise over one fifth of the nursing work force on Sundays. This shows the additional pressures in London and throughout the rest of the UK to maintain nurse staffing levels 'out of hours'

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Details were collected about the number of staff working at four 'snapshot' time periods: a weekday and weekend at noon and midnight, including the use of any bank and agency nursing staff. For the purposes of calculating the 'normal hours', use of bank and agency nursing staff data were analysed for the data from Wednesday at noon (Figure 5). 'Out of hours' use of bank and agency staff was calculated using the data from Wednesday at midnight, Sunday at midday and Sunday at midnight. In Figure 6 we present the data for midday on Sunday.

Why is this important?

PICUs need to be able to monitor whether they have adequate nursing staff available to run their unit efficiently. Use of bank and agency staff highlights problems with current staffing levels which may be due to staff illness or problems with staff retention. The efficiency of the unit may also be compromised in terms of team working and a lack of continuity of care. In addition these staff may have limited knowledge about unit policies, working practices and equipment and may not be able to administer medication until they have been assessed as competent. Their use also adds an additional financial burden to their hospital

The proportion of open beds in PICUs that were occupied during 'normal hours' at noon on a weekday during census week in November 2016 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?

High levels of occupancy were found across the UK & Republic of Ireland on a weekday at noon with England having an occupancy rate of 95% in IC & 90% in HD. Wales reported 100% occupancy for all critical care beds. Both Scotland & the Republic of Ireland reported occupancy levels greater than 85% for their intensive care beds.



FIGURE 7: PERCENTAGE OF FUNDED CRITICAL CARE BEDS OCCUPIED AT MIDDAY WEDNESDAY, NOVEMBER 2016

What does this mean?

Reported occupancy rates in paediatric intensive care were very high during 'normal hours' reflecting the increased activity in PICUs over recent years. This data will inform the current Paediatric Critical Care Review in England which is considering issues of access to the service.

Definition and methods

Information about bed occupancy is collected each year as part of the PICANet staffing study. As part of the survey, details were collected about the total number of open and funded 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 – Figure 7) and 'out of hours' (Wednesday at midnight, Sunday at midnight) were then calculated. In Figure 8 we present the data for midday on Sunday.

Why is this important?

Information about levels of bed occupancy are important for both the commissioners and providers of paediatric intensive care to ensure that there is adequate provision of paediatric critical care beds and is important information for the current Paediatric Critical Care review being carried out in England. PICS standard L3-207 states that average bed occupancy 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 a NHS Services Quality Dashboard measure (PICO 5a).

The proportion of open beds in PICUs that were occupied at noon on a weekend during the census week in November 2016 in the UK and Republic of Ireland. The number of open beds is the number of intensive care and high dependency beds on a PICU for whom staff were available.

What did we find?

Out of hours occupancy rates on at a weekend at midday showed little reduction compared to the rates reported during normal hours (see previous page) during census week. Occupancy rates for intensive care beds were very high for England, Wales and the Republic of Ireland at 91%, 100% and 93% respectively.



FIGURE 8: PERCENTAGE OF FUNDED CRITICAL CARE BEDS OCCUPIED AT MIDDAY SUNDAY, NOVEMBER 2016

What does this mean?

'Out of hours' occupancy rates in paediatric intensive care are very high, indicating the continued demand for high level of critical care throughout the week. This data will inform the current Paediatric Critical Care Review in England which is considering issues of access to the service.

Definition and methods

Information about bed occupancy is collected each year as part of the PICANet staffing study. As part of the survey, details were collected about the total number of open and funded 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 – Figure 7) and 'out of hours' (Wednesday at midnight, Sunday at midday and Sunday at midnight) were then calculated. In Figure 8 we present the data for midday on Sunday.

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Information about levels of bed occupancy are important for both the commissioners and providers of paediatric intensive care to ensure that there is adequate provision of paediatric critical care beds and is important information for the current Paediatric Critical Care review being carried out in England. PICS standard L3-207 states that average bed occupancy 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 a NHS Services Quality Dashboard measure (PICO 5a).

Case ascertainment means measuring how many admissions are reported to PICANet out of all admissions to a PICU: so, we check if we have missed any. We do this by checking our records against local records such as admission books or local computer systems. A 100% ascertainment would mean we received them all.

What did we find?

In the 14 PICUs we visited in 2016 we found that almost all admissions were reported to PICANet. We are confident that we have 99.9% case ascertainment. This means that based on the 20,000 admissions we are sent each year we estimate we would only miss at most around 20 (Figure 9 illustrates this).

FIGURE 9: ESTIMATED PERCENTAGE OF ALL ADMISSIONS REPORTED TO PICANET

99.9 % of admissions reported

Metric 1: Case ascertainmen

What does this mean?

By collecting data for almost <u>every</u> child that is admitted to a PICU in the UK and the Republic of Ireland, we can be sure that our findings represent a true picture of what happens in PICUs. If we had poor ascertainment we could not be certain about our conclusions as we may have missed some vital information.

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.

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 lot of admissions are 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 rates between PICUs. We are sure, however, that our very high ascertainment rate means that we can be confident about our analyses and interpretation of our findings. Some children need to be transported to a PICU for their care. We have calculated how long it takes for the specialist transport team to start their journey to pick up a child who needs urgent paediatric intensive care. We then calculated what proportion of these journeys started within an hour, 1-3 hours and over 3 hours.

What did we find?

Twelve out of 18 organisations managed to mobilise within 1 hour more than half the time: see Figure 10. Overall, nearly three quarters of journeys were started within 1 hour, with less than 1 in 10 journeys started more than 3 hours after the decision was made to transport the child (Figure 11).





FIGURE 11: NUMBER OF TRANSPORTS MOBILISED BY TIME TO MOBILISATION



What does this mean?

Most of the time, specialist transport teams take less than an hour to start their journey to pick up a child who requires urgent critical care. The Care Quality Commission have said that the target should be under 1 hour. When it takes longer this could be related to staff, equipment and/or bed availability.

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 1 hour. We measured the time from when they agreed to the transport, to the time they set off in the ambulance for what are called 'non-elective' admissions – these are the emergency admissions, and not planned transfers from one PICU to another or from a PICU to a district general hospital, for example.

Why is this important?

Any delay in in receiving intensive care could put the patient at risk as the referring hospital may not have the resources to look after a critically ill child. Persistent delays in getting the team mobilised may mean that there are insufficient resources in the transport organisation, it is just a very busy time or there are some other organisational issues that need to be addressed. By measuring the time it takes to mobilise the transport team over a long period of time, PICANet are able to monitor and report back on performance and enable the transport organisations to make changes to improve the quality of their service if necessary.

We recorded how many qualified staff were on duty and the level of care needed by children in PICUs at four census time points in November 2016. Current Paediatric Intensive Care Society Standards (2010/15) states a minimum number of 7.01 WTE* qualified nurses are needed to staff one level 3 critical care bed.

What did we find?

Just over half (55%) of PICUs in the UK and Republic of Ireland met the recommended nurse to patient ratio during 'normal hours' at midday on census Wednesday, but at midnight this reduced to 48%. Around two fifths of units met the standard at midday on census Sunday and one third at midnight.



FIGURE 12: PERCENTAGE OF PICUS MEETING RECOMMENDED LEVELS OF NURSING STAFF PER CRITICAL CARE PATIENT

* WTE means Whole Time Equivalent: this takes into account nurses working part-time.

What does this mean?

The data from the PICANet staffing census week suggest that just under half of the PICUs in the UK & Republic of Ireland fail to meet the recommended nurse staffing standard during 'normal hours' and up to two thirds of PICUs fail to do so during 'out of hours' periods. This data should inform the future planning of PIC.

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 III Children (5th Edition, December 2015). Staffing data is collected in the November of each year: the week beginning 21st November in 2016. Figure 12 presents the percentage of PICUs meeting the recommended level of nurse staffing per critical care patient at each of the four 'snapshot' time periods: a Wednesday at noon to represent 'normal hours' and Wednesday at midnight and Sunday at noon and midnight to represent 'out of hours' working.

The recommended number of nurses required, in order to provide the appropriate levels of care for the number and given dependency of the patients, is calculated according to the PICS Standards and the Paediatric Critical Care Healthcare Resource Group classification levels 1, 2 and 3 paediatric critical care. Level 1 Basic critical care, Level 2 Intermediate critical care, also known as High Dependency, requiring nurse to patient ratio of 1:2, Level 3 critical care requiring a nurse to patient ratio of 1:1.

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 7.01WTE'. Fewer units met the standard than in 2015: 55% in 2016 compared to 66% in 2015 during 'normal hours'.

We count the number of emergency readmissions within 48 hours for each PICU and compare it with the average for the UK and Republic of Ireland. We do this using the admission and discharge dates and times. The relative re-admission rate (Figure 13) allows us to compare PICUs with each other.

What did we find?

Over 300 children per year (around 2 out of every 100 admissions) are discharged from PICU but then re-admitted as an emergency within 48 hours (Table 5). Two PICUs, Q and V, have a higher re-admission rate than expected. It also suggests busier PICUs may have slightly higher readmission rates.

| Country | 2014 | 2015 | 2016 |
|--------------------------|-------------------|-------------------|-------------------|
| UK & Republic of Ireland | 344 (1.7%) | 310 (1.6%) | 319 (1.6%) |
| England NHS Non-NHS | 291 (1.8%) < 5 | 250 (1.6%) < 5 | 243 (1.5%) < 5 |
| Wales | < 5 | 14 (3.0%) | 6 (1.1%) |
| Scotland | 23 (1.6%) | 17 (1.3%) | 37 (2.5%) |
| Northern Ireland | 10 (2.0%) | 8 (1.3%) | 10 (1.5%) |
| Republic of Ireland | 17 (1.1%) | 19 (1.4%) | 21 (1.5%) |

TABLE 5: NUMBER OF EMERGENCY READMISSIONS WITHIN 48 HOURS

FIGURE 13: RELATIVE 48 HOUR EMERGENCY READMISSION RATE BY HEALTH ORGANISATION



What does this mean?

Emergency re-admission within 48 hours may mean that a child was discharged too early, although we do not have detailed information about why each child was readmitted. On investigating the data further, PICU Q has a higher readmission rate due to the way they recorded admissions in 2014-2015.

Definitions and methods

We defined an emergency readmission within 48 hours as any unplanned admission to the same PICU or another PICU within 48 hours of their last discharge from PICU. So if a child was admitted on the 1st March 2016 at 12:00 and discharged on the 2nd March 2016 at 17:00 but then admitted as an emergency (an unplanned admission) on the 4th March 2016 at 04:30, they would have been counted in our analysis as they returned to PICU after 35 ½ hours. We then counted 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 maximum acceptable rate of emergency readmissions within 48 hours so we used the average for all PICUs contributing to PICANet. We then used the funnel plot method described at the beginning of this report to assess if any PICU has a higher rate than expected, based on the overall average.

Why is this important?

Emergency readmission within 48 hours is seen as bad for the patient and for the PICU. For the patient it means that their health has got worse again in a short time and that they need further intensive care treatment, which can be stressful for them and their carers. For a busy PICU, each admission creates additional work. PICU Q have a high admission rate due to the way they record their admissions moving between high dependency and intensive care beds in the same unit in 2014-2015.

It should be noted that although emergency readmission is used as a quality indicator, we do not know the cause of the readmission so there is no way 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.

We compare mortality (death rates) between PICUs using a statistical method that accounts for how sick children were on admission. This is called risk adjustment. We calculate how many children we would expect to die and how many actually die to create what is called a risk-adjusted Standardised Mortality Rate or SMR.

What did we find?

Figure 14 shows the risk-adjusted SMR for all the PICUs in the UK and Republic of Ireland by number of admissions for 2015 and 2016. If any PICU falls above the curved line it indicates that their death rates are higher than expected and need to be investigated. No PICU has higher than expected mortality in 2015-2016.



FIGURE 14: RISK-ADJUSTED SMR FOR 2015-2016, BY HEALTH ORGANISATION

The 'risk-adjustment' method used to calculate expected mortality was the Paediatric Index of Mortality 3 (PIM3).

What does this mean?

Each year, a small number of children die in PICU. This figure shows that after taking into account how sick they were on admission, there are no PICUs who have death rates that are higher than expected.

Definitions and methods

Clinical data collected on admission is used in a statistical model to predict the probability that each child might die: the worse their 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 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 on PICU is quite 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. In last year's PICANet annual report we identified a statistical mortality outlier in one PICU. An independent panel investigated the causes of higher mortality and concluded it was because the PICU had an unusual 'case-mix' of children with complex conditions and that there was no indication that quality of care within PICU was low.

LONG TERM SURVIVAL AFTER DISCHARGE FROM PICU

Basic methodology

We know that very few children die in PICU, but there has been very little information on the long-term survival of children after they have been discharged. PICANet has linked the information collected from PICUs with the Office of National Statistics (ONS) to follow up the status of these children.

ONS notify PICANet if a child has died or moved to a different country. They only have information on children that live in England and Wales, so children that live in other countries were not included in this follow-up. Permission to link PICANet data to the ONS database was granted by the NHS Health Research Authority. All of the data is transferred securely and held in a very safe environment.

Linkage with ONS

PICANet sent details of all children who were living in England or Wales when they were admitted to a PICU between 1st November 2002 and 3rd December 2015 to ONS. ONS then matched these children with their database and sent death certificate details to PICANet for any child who had died. The rest of the children were flagged by ONS so that their status could be followed up over time. Updates have been sent to PICANet on a regular basis. The last update on these children was sent in November 2016.

We have carried out some preliminary analysis on these data to focus on 30-day as well as long-term survival overall and the differences in survival between broad ethnic groups as defined by the UK Census. We have not split these into smaller sub-groups as the numbers become small and make interpretation of point estimates difficult.

Note that these results relate to individual children following their last admission so death rates will be slightly higher than those quoted in the headline figures section of this report, as they relate to the number of deaths per admission.

Results

We were able to analyse data on 125,329 children who were matched with ONS. Table 6 below shows what happened to these children between 1st November 2002 and November 2016. Overall, 12% of children admitted to PICU died either in PICU or following discharge. Just under half of these deaths occurred in children who were under one year of age when admitted to PICU.

Nearly one in five (19%) children of South Asian ancestry admitted to PICU died in PICU or following discharge. Figure 15 illustrates the differences between different ethnic groups: 11.1% of South-Asian children died in PICU and 8.9% died following discharge. White children have the lowest death rates in PICU at 6.0%. Overall, South-Asian children admitted to PICU have an 83% higher risk of death compared to white children.

TABLE 6: DEMOGRAPHIC DETAILS FOR ENGLISH CHILDREN ADMITTED TO PICU BETWEEN 1ST NOVEMBER 2002 AND 3RD DECEMBER 2015 WHO SURVIVED AND THOSE WHO DIED IN PICU OR FOLLOWING DISCHARGE.

| | Alive | Dead |
|----------------------------|-----------------|----------------|
| | n=110,269 (88%) | n=15,060 (12%) |
| Sex, n (%) | | |
| Male | 62,646 (88.3) | 8,336 (11.7) |
| Female | 47,583 (87.6) | 6,712 (12.4) |
| Ambiguous | 27 (75.0) | 9 (25.0) |
| Unknown/ Missing | 13 (81.2) | 3 (18.8) |
| | | |
| Age at admission, n (%) | | |
| <1 year | 45,713 (86.9) | 6,908 (13.1) |
| 1-4 years | 29,201 (89.9) | 3,290 (10.1) |
| 5-10 years | 16,249 (88.8) | 2,057 (11.2) |
| 11-15 years | 16,327 (88.1) | 2,205 (11.9) |
| 16+ years | 2,775 (82.2) | 600 (17.8) |
| Missing | 4 (100.0) | 0 |
| Ethnicity, n (%) | | |
| White | 68,047 (89.1) | 8,361 (10.9) |
| Black | 4,588 (88.1) | 621 (11.9) |
| South Asian | 7,253 (81.0) | 1,703 (19.0) |
| Other | 30,381 (87.4) | 4,375 (12.6) |

FIGURE 15: IN-PICU AND POST-PICU DISCHARGE MORTALITY FOR ENGLISH CHILDREN ADMITTED TO PICU BETWEEN 1ST NOVEMBER 2002 AND 3RD DECEMBER 2015 BY ETHNIC GROUP.



Long term survival after discharge from PICU

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Table 7 below details mortality in PICU and at 30 days following discharge by age group. The 30 day mortality is higher for those admitted when they were under 1 year of age (2.1%) and also for those over 16 years (1.5%), compared with 1.2% for the other age groups.

| Age category | Number of admissions | In-PICU deaths n (%) | Number of children with 30 days discharge information | Deaths within 30 days of discharge n (%) |
|-----------------|-------------------------|-------------------------|--|--|
| < 1 year | 52,621 | 4,441 (8.4) | 48,163 | 1,025 (2.1) |
| 1-4 years | 32,491 | 1,763 (5.4) | 30,574 | 380 (1.2) |
| 5-10 years | 18,306 | 1,050 (5.8) | 17,128 | 206 (1.2) |
| 11-15 years | 18,532 | 1,046 (5.6) | 17,409 | 201 (1.2) |
| 16+ years | 3,375 | 186 (5.5) | 3,179 | 49 (1.5) |
| Missing | 4 | 0 | 0 | 0 |

TABLE 7: IN-PICU AND 30 DAY MORTALITY FOR ENGLISH CHILDREN ADMITTED TO PICU BETWEEN 1ST NOVEMBER 2002 AND 3RD DECEMBER 2015

Interpretation

These results are preliminary findings from our analysis of death certificate data supplied by ONS. It is clear that not all children who die following an admission to PICU die on the unit and this is not surprising given that about two-thirds of PICU admissions are for children who have life-limiting conditions. Our long-term follow-up has revealed that the higher mortality in children of south Asian ancestry in PICU persists following discharge. We have previously reported an excess risk adjusted mortality for in-PICU mortality in south Asian children for which there was no adequate explanation⁴ and these data suggest that there should be further investigation into this finding that extends beyond the PICU.

A more comprehensive and sophisticated analysis of these data is underway and will be submitted to a peer-review journal for publication.

APPENDIX 1

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 Sick Children, Glasgow started submitting data in December 2004 and March 2007 respectively. The Royal Belfast Hospital for Sick Children joined in April 2008 and Our Lady's Children's Hospital, Crumlin and the Children's University Hospital, Temple Street, both based in Dublin, have submitted anonymised data to PICANet since 2010. 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 of the online annual report section of the PICANet website.

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.

(http://www.hra.nhs.uk/documents/2017/04/cag-piag-register-march-2017.xls).

Ethics approval has been granted by the Trent Medical Research Ethics Committee, ref. 05/MRE04/17 +5.

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. We also have a PIC Families Group to consider the impact of admission to intensive care on children and their families. Appendices B, C and D provide a full list of CAG, SG and PIC Families group 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, Our Lady's Children's Hospital, Crumlin is governed by a Board of Directors and is a company limited by guarantee. Temple Street Children's University Hospital (TSCUH) is incorporated as a private limited company. Both receive funding from the Health Services Executive, charitable and private sources.

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 33 PICUs and 11 specialist transport organisations currently submitting data to PICANet (The Royal Alexandra Hospital, Brighton), is included in this report for 2014 but is no longer submitting data as it is not commissioned as a paediatric intensive care unit.

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 personal details of each child including their name, age, date of birth, NHS number, address and ethnic group; it also records where children are admitted from, their 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 dat*a 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 about 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 and patient and family experiences:

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

Parent/Carer satisfaction data is collected on an annual basis as part of the work programme of the PICU families group.

Analytical techniques

Statistical techniques used include simple cross tabulations, the use of logistic regression to recalibrate the mortality risk adjustment model based on a rolling 3-year data window; 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. Cox-proportional hazards models and Kaplan-Meier graphs are used to assess survival trends using the mortality data obtained from the NHS Health and Social Care Information Centre to assess longer term survival. More sophisticated statistical techniques such as random effects logistic regression, propensity score matching and latent class analysis have been proposed to enable this rich dataset to be explored with greater subtlety. This year, we have calculated risk adjusted SMRs using the new version of the Paediatric Index of Mortality, PIM3⁵ but only for 2015 and 2016, as complete data is only available for these years.

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 is validated on-line 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.

⁵ Straney L, Clements A, Parslow RC, Pearson G, Shann F, Alexander J, Slater A, Group APS, the Paediatric Intensive Care Audit N. Paediatric index of mortality 3: an updated model for predicting mortality in pediatric intensive care. Pediatr Crit Care Med 2013;14(7):673-81

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 has 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. We have provided baseline data for the two largest clinical trials in paediatric intensive care (CHiP (Control of Hyperglycaemia in Paediatric Intensive Care) and CATCH (CATheter infections in Children)). PICANet has also 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. Over the next few years we will be working closely with the NIHR funded DEPICT study, which is investigating the effect of differences in access to emergency paediatric intensive care and care during transport on clinical outcomes and patient experience.

Small number policy

Publication of PICANet data is subject to scrutiny for 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:

(http://www.picanet.org.uk/Documentation/Policies/PICANet_Policy_on_Units_ly ing_outside_the_control_limits%205_oct2015.pdf), which relates specifically to assessment of risk-adjusted mortality. We also follow the more detailed guidance on outliers subsequently developed by HQIP published in 2011. On three specific occasions, 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. Last year we outlined how we dealt with an outlier that was not attributable to data quality and included a response from the PICU detailing their internal findings and the result of an external review.

Links with the clinical community, patients and their families

The PICANet PICU Families Group currently has four Lay Representatives who are the parents of children who are currently or have previously received paediatric intensive care. 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 to support PICANet and its work and to request 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.

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