Increasing admissions to paediatric intensive care units in England and Wales: more than just rising a birth rate

Peter Davis, ¹ Christopher Stutchfield, ¹ T Alun Evans, ^{2,3} Elizabeth Draper^{2,3}

Objective To determine the number of individual children admitted to Paediatric Intensive Care Units (PICUs) in England and Wales between 2004 and 2013 and to investigate potential factors for any change over time, including ethnicity.

Methods Anonymised demographic and epidemiological data were extracted from the Paediatric Intensive Care Audit Network (PICANet) database and analysed for all children resident in England and Wales admitted to PICUs of National Health Service (NHS) hospitals in those countries between 2004 and 2013. Population data, including births, were obtained from the Office of National Statistics and analysed. Predicted numbers of children admitted to PICU were compared with actual admissions, averaged over 3-year periods. **Results** Increasing numbers of individual children were admitted to PICUs in England and Wales between 2004 and 2013. The largest increases were among younger children (0–5 years) and those with primary respiratory or cardiac diagnoses. They were also greatest in regions with the most mothers born overseas. From 2009 onwards, more children were admitted to PICUs than predicted, separate from overall population growth, South Asian ethnicity or requirement for ventilation. **Conclusions** An additional increase in the number of children from England and Wales admitted to PICU from 2009 onwards is not explained by a rising child population or an increased risk of admission among South Asian children. There was no evidence of a reduction in the admission criteria to PICUs. Given healthcare funding in England and Wales, continued increases would present a challenging prospect for both providers and commissioners of these services.

INTRODUCTION

In the past 20 years, paediatric intensive care (PIC) services in the UK have changed very significantly. Alongside advances in medical and surgical care, ¹⁻⁴ the number of admissions to Paediatric Intensive Care Units (PICUs) has been increasing over time. ⁵ Concurrently, there have been potential changes in the population at risk, in terms of a rising birth rate, ⁶ increasing numbers surviving extreme prematurity, ⁷ greater international immigration, ⁸ plus higher admission rates to PICU for children of South Asian ethnicity compared with non-South Asians. ⁹

Given these various issues, it is important to understand their possible effects on the numbers of individual children admitted to PICUs, and consider other possible factors, so as to facilitate healthcare planning, resource allocation and delivery of care.

What is already known on this topic?

- The number of live births per year in England and Wales has increased by approximately 100 000 since 2000.
- ➤ Admissions to Paediatric Intensive Care Units (PICUs) in England and Wales have increased since the inauguration of Paediatric Intensive Care Audit Network in 2002.
- ► Children of South Asian ethnicity are at increased risk of PICU admission and mortality.

What this study adds?

- ➤ Without admission criteria changing, the numbers of individual children admitted annually for Paediatric Intensive Care rose faster than the child population, across all age groups.
- The risk of requiring invasive ventilation has increased for children under 5 years of age, particularly among those with primary respiratory or cardiovascular diagnoses.
- ➤ The largest increases in individual children admitted to Paediatric Intensive Care Units occurred in those English regions with the greatest numbers of live births to mothers of Eastern European origin.

OBJECTIVES

This study aimed to determine the number of individual children being admitted to PICUs in England and Wales between 2004 and 2013, compared with the overall child population, and to investigate potential factors for any changes over that period, including ethnicity.

METHODS

Data for all PICU admissions from the Paediatric Intensive Care Audit Network (PICANet) database was analysed for all children resident in England or Wales, aged 0–15 years of age admitted to PICUs of National Health Service (NHS) hospitals in England and Wales between 2004 and 2013. PICANet has MREC ethics committee approval (05/MRE04/17) and National Information Governance Board (4-07(c)/2002-PICANet) approvals to collect patient identifiable data without informed consent.

Data collected for each child included age (stratified as <1 year, 1–5 years, 6–15 years),

¹Paediatric Intensive Care Unit, Bristol Royal Hospital for Children, Bristol, UK ²Department of Health Sciences, University of Leicester, Leicester,

³Paediatric Intensive Care Audit Network (PICANet), Universities of Leeds and Leicester, Leicester, III

Correspondence to

Dr Peter Davis, Paediatric Intensive Care Unit, Bristol Royal Hospital for Children, Upper Maudlin Street, Bristol BS2 8BJ, UK; peter.davis@uhbristol.nhs.uk

Received 10 August 2017 Accepted 14 August 2017



To cite: Davis P, Stutchfield C, Evans TA, et al. Arch Dis Child Published Online First: [please include Day Month Year]. doi:10.1136/ archdischild-2017-313915

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sex, diagnostic group (blood and lymph, body wall and cavities, cardiac, endocrine/metabolic, gastrointestinal, infection, multisystem, musculoskeletal, neurological, oncology, other, respiratory, trauma), mode of ventilation during PICU admission (invasive, non-invasive/continuous positive airway pressure (CPAP)), country or region of home address (England: East Midlands, East of England, London, North East, North West, South Central, South East Coast, South West, West Midlands, Yorkshire and the Humber; Wales) and outcome at discharge from PICU (alive or dead). Readmissions within a calendar year were not counted.

Population data for both mothers and children were obtained from the Office of National Statistics and analysed in relation to the data obtained from PICANet.

In order to investigate the effect of the changing population structure in England and Wales, the 'Understanding Populations Trends and Processes' model was used to create an estimate from available UK Census data of how many children by age group were alive each year, including estimates for two main ethnic groups: South Asian and non-South Asian. 10 This provided the denominators to allow for prediction of how many children require paediatric intensive care each year and can be accessed via the ETHPOP project website. 11 To define ethnicity in the PICANet dataset of admissions, any child who had been entered as 'Indian', 'Pakistani', 'Bangladeshi' or 'Any other Asian Background' was also categorised as South Asian. Further, South Asian children were identified by using two versions of name analysis software, 'Nam Pehchan' and 'SANGRA'. 13 Any child with a matching level of three or more in 'Nam Pehchan' and the output from 'SANGRA' was classified as South Asian.

To minimise the impact of year-on-year fluctuations in admissions, rolling 3-year averages were calculated. The number of children with multiple PICU admissions within 3-year periods was also calculated.

To establish if the increase in PICU admissions was solely due to a rising population in England and Wales, age-stratified admission rates were calculated for the total population and then for the two specified ethnic groups. As a baseline, the 2004–2006 rates were applied to subsequent years so that expected numbers of children admitted could be compared against the actual number of individual children admitted per year, both for the total number of children and for those who were invasively ventilated.

RESULTS

An annual increase in the number of children admitted to PICU was noted throughout the study period using the 3-year averages. The preponderance of males admitted to PICU remained constant throughout the study period (male to female ratio of 1.2:1), which was replicated when only considering children invasively ventilated on PICU (a proxy measure for a higher level of critical care). Despite absolute numbers of deaths on PICU increasing by 8% over the study period, the overall annual

mortality rate for individual children admitted to PICU dropped from 7.7% in 2004–2006 to 7.3% in 2011–2013.

Infants (<1 year of age) accounted for almost half of the admissions to PICU each year (table 1). Each age group experienced a rise in individual patient admissions during the study period. The most significant rise was seen for the youngest children under 1 year and in those aged 1–5 years (table 1). By comparison, the total population in England and Wales for those age groups rose by 11% and 17.7%, respectively, over the same time period, whereas among 6–15 year olds, the total population dropped by 6.2%.

In terms of primary diagnosis underlying PICU admission, the largest absolute increases in the numbers of children admitted were cardiovascular or respiratory conditions, which when evaluating the 2004–2006 to 2011–2013 3-year averages, equates to over 1000 more children per year in the final period compared with the earliest. Most of the rise in children admitted with cardiovascular primary diagnoses was among infants, equating to an average of 300 more children per year under 1 year of age over the study period. For respiratory primary diagnoses, the main increases were in children under 1 and in children of 1–5 years of age, with each equating to an average additional 300 children admitted to PICU with these conditions during a calendar year. There were also notable increases in the number of children admitted to PICU with a primary musculoskeletal or infective diagnosis (table 2).

The number of children supported by either invasive or non-invasive ventilation, including CPAP, increased significantly over the 10 years, by on 3-year averages 18.0% and 91.0%, respectively, and generally in line with the overall increase in numbers of children admitted to PICU (figure 1).

Most of the rise in invasive ventilation was in infants under 1 year of age (approximately difference over 10 years of 800 per year or 20.9%) and in the 1–5 years of age group (approximately difference of 500 per year or 23.8%). Among children aged 6–15 years, the rise was much smaller (4.8%). Overall, the percentage of children admitted to PICU undergoing invasive ventilation increased by 2.3% from 70.5% in 2004–2006 to 72.8% in 2011–2013. The number of children admitted to PICU supported only with non-invasive ventilation, including CPAP, nearly doubled over the 10-year study period across all age groups.

Geographical analysis of data showed that the numbers of children from England admitted to PICU increased by 14.7% over the study period, while for children with a home address in Wales, the increase was only 2.2%. The largest rises were seen in the English regions of West Midlands (22.5%), East of England (22.7%), London (30.8%), South East Coast (11.9%) and South Central (43.2%), with other regions showing little or no change. When studying only those children who were invasively ventilated, the rise in the numbers admitted from England was even greater over the study period at 18.7%, while for children from Wales it was just 5.4%. Across the five regions of England with the largest increases in children admitted to PICU, the rise for only those

Table 1 Total numbers of individual children from England and Wales admitted to Paediatric Intensive Care Unit in England and Wales per year by age group category

	2004–2006	2005–2007	2006–2008	2007–2009	2008– 2010	2009–2011	2010–2012	2011–2013	3 year % change
<1 year old	4761	4807	4917	5111	5253	5367	5490	5465	14.8%
1–5 years old	3038	3126	3217	3336	3411	3477	3532	3632	19.6%
6–15 years old	2754	2774	2801	2874	2882	2903	2932	2968	7.8%
Total children admitted	10553	10707	10 935	11 321	11 546	11 747	11 954	12 065	14.3%

Table 2 Total numbers of individual children from England and Wales admitted to Paediatric Intensive Care Unit in England and Wales per year by primary diagnosis group

	2004–2006	2005–2007	2006–2008	2007–2009	2008–2010	2009–2011	2010–2012	2011–2013	3 year % change
Blood/lymphatic	82	98	114	119	112	107	107	114	39.0%
Body wall and cavities	233	237	235	252	249	246	222	208	-10.7%
Cardiovascular	3104	3125	3172	3202	3286	3409	3476	3528	13.7%
Endocrine/metabolic	246	273	290	296	300	305	312	316	28.5%
Gastrointestinal	712	706	742	774	801	795	789	750	5.3%
Infection	544	571	600	651	684	674	646	634	16.5%
Multisystem	22	26	26	23	24	28	32	35	59.1%
Musculoskeletal	390	395	405	414	405	418	436	490	25.6%
Neurological	1275	1292	1317	1342	1351	1330	1354	1355	6.3%
Oncology	396	397	400	393	396	402	415	401	1.3%
Other	473	486	506	523	528	525	554	595	25.8%
Respiratory	2501	2549	2630	2855	2921	3019	3128	3205	28.1%
Trauma	513	491	464	438	425	419	411	382	-25.5%
Unknown	62	61	34	39	64	70	72	52	-16.1%
Totals	10553	10707	10935	11 321	11 546	11 747	11 954	12 065	

children undergoing invasive ventilation was remarkably close at between 19.5% and 22%. These were also the five regions with the highest proportions of mothers born outside of the UK.

Children of South Asian ethnicity were more likely to be admitted to PICU during a calendar year across all age ranges, compared with those of non-South Asian ethnicity. Average admission rates for South Asian children to PICU per 1000 of population over the 10 years were approximately 75% higher for infants, 107% higher for children of 1–5 years and 93% higher for 6–15 year olds. The most marked increase in admission rates per 1000 population over the 10 years was seen in the 6–15 year olds of South Asian ethnicity, which for a 3-year average increased by 37% from 0.67 per 1000 in 2004–2006 to 0.92 per 1000 in 2011–2013.

As a proportion of all PIC admissions, those children who were readmitted to PICU over the subsequent 3-year calendar (January–December) period, remained relatively stable between 2004–2006 and 2011–2013. However, the actual number of readmissions

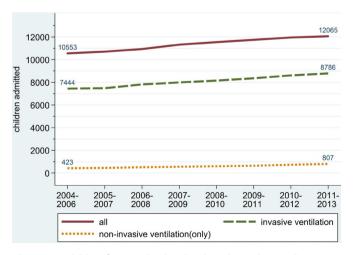


Figure 1 Children from England and Wales admitted to Paediatric Intensive Care Units (PICU) in England or Wales per year supported by invasive or non-invasive ventilation compared to the total number of children admitted to PICU per year (excluding readmissions within calendar year).

increased by 21% overall from 10529 in 2004–2006 to 12727 in 2011–2013. On the same basis, overall numbers of admissions across these 3-year periods, including readmissions, increased by 14.3% between 2004–2006 and 2011–2013.

Finally, from 2009 onwards, there is a trend for increasingly more individuals being admitted to PICU than would have been anticipated. This development appears to be separate from the effect of overall population growth and ethnicity, and even holds true when only studying children who were invasively ventilated (figure 2).

DISCUSSION

Over the 10 years from 2004 to 2013, there was a noticeable increase in the number of children resident in England or Wales being admitted annually to PICUs. A rising birth rate 14 15 does not wholly account for the increase in patient admissions, as

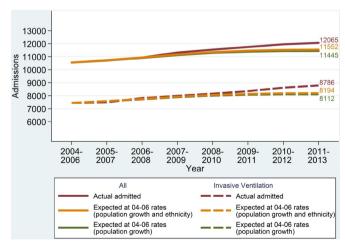


Figure 2 A comparison of the numbers of children from England or Wales actually admitted to Paediatric Intensive Care Units in England and Wales (excluding readmissions within calendar year) by rolling 3-year average (both all and invasive ventilation only) to the number expected if the admission rates per year per age group of the child population (0–15) based on South Asian or not South Asian ethnicity had stayed the same as 2004–2006.

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the percentage increase in children admitted was greater than the age-specific population growth. Meanwhile ventilation rates have increased over this time, so any increase in PICU admissions cannot be attributed to a lower admittance threshold. The increased centralisation of intensive care provision for children in PICUs occurred before our study period, ¹⁶ while newer regional initiatives to manage more children locally for very brief intensive care support ¹⁷ ¹⁸ may have had the opposite effect on admissions.

There was a noticeable increase in the number of children with respiratory diagnoses requiring admission to PICU. As the live birth rate increased by approximately 15% in 10 years in England and Wales, greater numbers of infants were at increased risk of respiratory compromise with viral or bacterial infections.¹⁹ Much of the growth in birth rates over this period was to mothers born outside the UK, who as a percentage of all births increased from 20% to 25%. 20 Children of South Asian ethnicity are at increased risk of admission to PICU and of worse outcomes, with a significantly higher mortality rate. 9 Our findings suggest that this group does not explain the rise in children needing admission to PICU from 2009 onwards. However, there has also been major migration from Eastern Europe, particularly mothers of Polish origin, who by 2013 constituted 3% of all live births in England and Wales, increasing from 2000 to 20000 per year over the study period.²¹ Notably, the largest regional increases in PICU admissions were where the greatest proportions of live births to mothers from outside the UK occurred, with among the highest numbers of live births to mothers from Eastern Europe (West Midlands, East of England, London, South East Coast and South Central).²

PICU increasingly cares for a more vulnerable and complex patient population, with increased numbers of children in England with life-limiting conditions, ²² including those with single ventricle circulations needing staged palliative cardiac procedures. The number of these operations increased by 40% over the study period, ^{23 24} a possible factor in the rise in cardiac diagnosis admissions. Different religious or cultural expectations of the treatment for life-limiting conditions, including attitudes towards termination of pregnancy and palliative care among immigrant populations, ²⁵ as well as wider shifts in society, ^{26 27} may also be influencing the number of children with these conditions admitted to PICU.

While absolute numbers of premature births remained relatively stable over the study period, 14 15 survival for extremely premature babies improved, with more preterm survivors at risk of chronic health problems, 28 29 including admission to PICU. 19 30 They also contribute to the rising proportion of children admitted to hospital with complex comorbidities, 31 who constitute 75% of sepsis cases on PICU. 32 This may explain the rise in primary infection diagnoses, despite the introduction of conjugate vaccines against *Neisseria meningitidis* and *Streptococcus pneumoniae* causing rates of septicaemia and meningitis to fall. 33 Additionally, children with severe neurodisability have greater levels of respiratory bacterial colonisation, 34 increasing the risk of needing ventilation. Children with neurodisability may also have contributed to the increased number of musculoskeletal admissions, most of which relate to elective scoliosis surgery in the oldest age group. 5

Although the number of PICU deaths increased by 8%, the percentage of individual children admitted to PICU who died fell. Increased survival may be due to improvements in intensive care, or changes in parental expectations, leading to more children surviving with significant morbidity.^{35 36} An expanding population of children with complex, chronic and life-limiting

conditions, who are at risk of clinical deterioration, particularly among infants, ³⁷ will steadily increase the numbers of children at greater risk of PICU admission. ^{36 37}

Over the 10-year study period, we identified more individual children being admitted to PICU, with a noticeable increase above expected numbers from 2009 onwards, while the average annual PICU bed days rose 22% in England and Wales over the study period.⁵ Over the period from 2004 to 2009, public healthcare spending in the UK increased by 8.3% per annum. However, from 2009 onwards, it grew at just 1.9%.³⁸ Increasing numbers of critically ill children requiring PIC in England and Wales, including greater numbers of children with complex chronic comorbidities and prolonged lengths of stay,³⁹ 40 will prove challenging both for PIC services and commissioners, as increased demand potentially outstrips resource.

Limitations of the study

Possible limitations to this study include any changes in service provision for PIC during the study period. However, the only change of any note was the establishment of one smaller PICU in London, whose data was included in the PICANet data from 2007 onwards. Data used for population predictions and live birth rates were the most up-to-date available from the Office for National Statistics. Similarly, for South Asian ethnicity data, recording of ethnicity within the PICANet dataset has been incomplete, and while a combination of Nam Pehchan¹² and SANGRA¹³ has been used in other peer-reviewed publications to identify children of South Asian origin, it is accepted that there is no available information on the reliability of these name analysis programmes in relation to mixed Asian ancestry, and obvious misclassifications have been previously noted with Nam Pehchan.⁹

CONCLUSION

Using data from PICANet and 3-year averages to reduce any between year variation, we have identified a significant and consistent increase in the numbers of individual children from England and Wales admitted to PICUs over a 10-year period from 2004 to 2013, unrelated to any reduction in admission criteria, as invasive ventilation rates increased over this time. From 2009 onwards, an additional increase was not explained by either population growth, rising birth rate or the increased likelihood of PICU admission for children of South Asian ethnicity. This coincided with a time of greater financial stringency within the NHS, complicating an already testing situation for providers and commissioners of PIC services in England and Wales, and given the increasing number of children with chronic, complex conditions, is a challenge that is likely to continue into the future.

Acknowledgements We would like to thank all the staff in participating hospitals who have collected data for PICANet. We are grateful to the members of the PICANet Steering Group and Clinical Advisory Group. A list of contributing centres and Steering Group and Clinical Advisory Group members may be found at http://www.picanet.org.uk/.

Contributors PJD initially conceived the study and with CJS obtained the initial data from PICANet and the Office of National Statistics, from which a first draft of the manuscript was completed. In discussion between all the authors, further data analyses were performed by AE and ESD on the PICANet data. All authors were involved in the subsequent versions of the manuscript and contributed substantially to its revision and approved its final version.

Funding The PICANet audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme (NCA). 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 and, in particular, to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage

and develop the NCA Programme, comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. PICANet is funded by NHS England, Health Commission Wales Specialised Services, NHS Lothian / National Service Division NHS Scotland, the Royal Belfast Hospital for Sick Children, The National Office of Clinical Audit, Republic of Ireland and HCA Healthcare.

Competing interests None declared.

Patient consent PICANet has MREC ethics committee approval (05/MRE04/17) and National Information Governance Board (4-07(c)/2002-PICANet) approvals to collect patient identifiable data without informed consent.

Ethics approval MREC ethics committee approval (05/MRE04/17)

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement All data were obtained either from PICANet or from publically available data from the Office of National Statistics. There is a data access request procedure for all analyses relating to PICANet data. This was followed with approval from the PICANet Clinical Advisory Group as per their Terms of Reference. An updated version of the procedure is available on the PICANet website: www.picanet.org.

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REFERENCES

- 1 Pearson G, Shann F, Barry P, et al. Should paediatric intensive care be centralised? Trent versus Victoria. Lancet 1997;349:1213–7.
- 2 Pearson G, Barry P, Timmins C, et al. Changes in the profile of paediatric intensive care associated with centralisation. *Intensive Care Med* 2001;27:1670–3.
- 3 Ramnarayan P, Thiru K, Parslow RC, et al. Effect of specialist retrieval teams on outcomes in children admitted to paediatric intensive care units in England and Wales: a retrospective cohort study. Lancet 2010;376:698–704.
- 4 Ramnarayan P, Polke E. The state of paediatric intensive care retrieval in Britain. Arch Dis Child 2012;97:145–9.
- 5 Paediatric Intensive Care Audit Network. A decade of data: Universities of Leeds and Leicester, 2014. published September.
- 6 Office for National Statistics. Birth summary tables, England and Wales. 2014 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2015-07-15 (accessed 10 Aug 17)
- 7 Seaton SE, King S, Manktelow BN, et al. Babies born at the threshold of viability: changes in survival and workload over 20 years. Arch Dis Child Fetal Neonatal Ed 2013;98:F15—F20.
- 8 Office of National Statistics. Migration statistics quarterly report, November 2014. London, 2014. http://www.ons.gov.uk/ons/dcp171778_386531.pdf. (accessed 10 Aug 2017).
- 9 Parslow RC, Tasker RC, Draper ES, et al. Epidemiology of critically ill children in England and Wales: incidence, mortality, deprivation and ethnicity. Arch Dis Child 2009;94:210–5.
- Wohlund P, Rees P, Norman P, et al. Ethnic population projections for the UK and local areas 2001–2051. Leeds: University of Leeds, 2010. Working paper 10/2.
 Wohlund P, ETHPOP database ESRC follow on fund "ethnic group population."
- 11 Wohlund P, . ETHPOP database, ESRC follow on fund "ethnic group population trends". www.ethpop.org. (accessed 11Jun 2014).
- 12 Pehchan N. Bradford Health Authority and City of Bradford Metropolitan District Council. A program to identify and analyse South Asian names, v 2.1. 2002. Bradford, UK: City of Bradford Metropolitan District Council.
- 13 Nanchahal K, Mangtani P, Alston M, et al. Development and validation of a computerized South Asian Names and Group Recognition Algorithm (SANGRA) for use in British health-related studies. J Public Health Med 2001;23:278–85.
- 14 The National Archive. UK Government Web Archive. http://www.ons.gov.uk/ons/rel/child-health/gestation-specific-infant-mortality-in-england-and-wales/2006/tables-gestation-specific-infant-mortality-2006.xls (accessed 10 Aug 2017).
- 15 Revisions Notice. Gestation specific infant mortality. 2012 http://www.ons.gov.uk/ ons/rel/child-health/gestation-specific-infant-mortality-in-england-and-wales/2012/ rft-table-1.xls (accessed 10 Aug 2017).

- 16 Ramnarayan P, Patel K, Pappachan J, et al. Characteristics and outcome of children admitted to adult intensive care units in England, Wales and Northern Ireland (1996-2011). Intensive Care Med 2013;39:2020–7.
- 17 Behjati S, Jamieson K, Montgomery M, et al. Do paediatric high dependency units in district general hospitals improve patient care? A local review of children presenting with seizures. Arch Dis Child 2012;97:582.1–582.
- 18 Davison KE, Cooper S. Management of children intubated for status epilepticus: current practice in West Yorkshire. Arch Dis Child 2012;97:855.
- 19 O'Donnell DR, Parslow RC, Draper ES. Deprivation, ethnicity and prematurity in infant respiratory failure in PICU in the UK. Acta Paediatr 2010;99:1186–91.
- 20 The National Archives. UK Government web archive. http://www.ons.gov.uk/ons/rel/vsob1/parents-country-of-birth-england-and-wales/2013/stb-births-by-cob-2013. html#tab-Live-Births-to-UK-and-Non-UK-Born-Women (accessed 10 Aug 2017).
- 21 The National Archives. http://www.ons.gov.uk/ons/rel/vsob1/parents-country-of-birth-england-and-wales/2013/stb-births-by-cob-2013.html#tab-Country-of-Birth-of-Foreign-Born-Mothers (accessed 10 Aug 2017).
- 22 Fraser LK, Miller M, Hain R, et al. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics* 2012;129:e923–e929.
- 23 National Congenital Heart Disease Audit Website. National Institute for Cardiovascular Outcomes Research nicor-helpdesk@bartshealth.nhs.uk national congenital heart disease audit website. https://nicor4.nicor.org.uk/CHD/an_paeds. nsf/WBenchmarksYears?openview&RestrictToCategory=2015&start=1&count=500 (accessed 10 Aug 2017).
- 24 Brown KL, Crowe S, Franklin R, et al. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. Open Heart 2015:2:e000157.
- 25 Pady C, Subramanian G. Audit of the cost of futile invasive care in Paediatric Intensive Care. Arch Dis Child 2012;97(Suppl 1):A169.2—A169.
- 26 Hardart MK, Truog RD. Spinal muscular atrophy type I. Arch Dis Child 2003:88:848–50.
- 27 Bush A, Fraser J, Jardine E, et al. Respiratory management of the infant with type 1 spinal muscular atrophy. Arch Dis Child 2005;90:709–11.
- 28 Marlow N, Bennett C, Draper ES, et al. Perinatal outcomes for extremely preterm babies in relation to place of birth in England: the EPICure 2 study. Arch Dis Child Fetal Neonatal Ed 2014;99:F181–F188.
- 29 Costeloe KL, Hennessy EM, Haider S, et al. Short term outcomes after extreme preterm birth in England: comparison of two birth cohorts in 1995 and 2006 (the EPICure studies). BMJ 2012;345:e7976.
- 30 Yates H. G50 admission of ex-premature babies to PICU in their first two years of life. Arch Dis Child 2013;98(Suppl 1):A27.
- 31 Burns KH, Casey PH, Lyle RE, et al. Increasing prevalence of medically complex children in US hospitals. Pediatrics 2010;126:638–46.
- 32 Weiss SL, Fitzgerald JC, Pappachan J, et al. Global epidemiology of pediatric severe sepsis: the sepsis prevalence, outcomes, and therapies study. Am J Respir Crit Care Med 2015;191:1147–57.
- 33 Martin NG, Sadarangani M, Pollard AJ, et al. Hospital admission rates for meningitis and septicaemia caused by Haemophilus influenzae, Neisseria meningitidis, and Streptococcus pneumoniae in children in England over five decades: a populationbased observational study. Lancet Infect Dis 2014;14:397–405.
- 34 Trinick RE, Bunni L, Thorburn K, et al. An observational study examining the relationship between respiratory symptoms, airway inflammation and bacteriology in children with severe neurodisability. PLoS One 2015;10:e0124627.
- 35 Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics* 2010;126:647–55.
- 36 Namachivayam P, Shann F, Shekerdemian L, et al. Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward. Pediatr Crit Care Med 2010;11:549–55.
- 37 Jarvis S, Parslow RC, Carragher P, et al. How many children and young people with life-limiting conditions are clinically unstable? A national data linkage study. Arch Dis Child 2017;102:131–8.
- 38 The NAtional archives. Expenditure on Healthcare in the UK. 2012 http://www.ons. gov.uk/ons/rel/psa/expenditure-on-healthcare-in-the-uk/2012/index.html (accessed 09 Nov 2016).
- 39 Edwards JD, Houtrow AJ, Vasilevskis EE, et al. Chronic conditions among children admitted to U.S. pediatric intensive care units: their prevalence and impact on risk for mortality and prolonged length of stay. Crit Care Med 2012;40:2196–203.
- 40 O'Brien S, Nadel S, Almossawi O, et al. The impact of chronic health conditions on length of stay and mortality in a general PICU. Pediatr Crit Care Med 2017;18:1–7.