openheart Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010

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ABSTRACT

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case mix for paediatric

Objectives: To explore changes over time in the 30day mortality rate for paediatric cardiac surgery and to understand the role of attendant changes in the case mix.

Methods, setting and participants: Included were: all mandatory submissions to the National Institute of Cardiovascular Outcomes Research (NICOR) relating to UK cardiac surgery in patients aged <16 years. The χ^2 test for trend was used to retrospectively analyse the proportion of surgical episodes ending in 30-day mortality and with various case mix indicators, in 10 consecutive time periods, from 2000 to 2010. Comparisons were made between two 5-year eras of: 30-day mortality, period prevalence and mean age for 30 groups of specific operations.

Main outcome measure: 30-day mortality for an episode of surgical management.

Results: Our analysis includes 36 641 surgical episodes with an increase from 2283 episodes in 2000 to 3939 in 2009 (p<0.01). The raw national 30-day mortality rate fell over the period of review from 4.3% (95% CI 3.5% to 5.1%) in 2000 to 2.6% (95% CI 2.2% to 3.0%) in 2009/2010 (p<0.01). The case mix became more complex in terms of the percentage of patients <2.5 kg (p=0.05), with functionally univentricular hearts (p<0.01) and higher risk diagnoses (p<0.01). In the later time era, there was significant improvement in 30-day mortality for arterial switch with ventricular septal defect (VSD) repair, patent ductus arteriosus ligation, Fontan-type operation, tetralogy of Fallot and VSD repair, and the mean age of patients fell for a range of operations performed in infancy.

Conclusions: The raw 30-day mortality rate for paediatric cardiac surgery fell over a decade despite a rise in the national case mix complexity, and compares well with international benchmarks. Definitive repair is now more likely at a younger age for selected infants with congenital heart defects.

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INTRODUCTION

There has been strong interest in the outcome of paediatric cardiac surgery in the UK since the 1990s, when a high mortality

KEY MESSAGES

What is already known about this subject?

- There is a high level of public interest in the outcomes of paediatric cardiac surgery.
- The focus of this interest has been on the merits and difficulties of comparing outcomes between different units, with little attention on raw mortality at a national level.
- Understanding of the factors underpinning short-term surgical risk for paediatric cardiac surgery has improved in recent years.

What does this study add?

- While the number of procedures performed nationally in the UK has increased over the last decade, the 30-day mortality rates for paediatric cardiac surgery have fallen. Mortality rates are low and compare favourably with current data from other international databases.
- The improvement in short-term outcomes is not explained by lower risk case mix, since data indicate that the children operated on have increased in complexity.
- There has been a trend towards earlier definitive repair in infancy for a range of conditions in the recent era.

How might this impact on clinical practice?

The very low mortality rates at 30 days must shift our focus now towards measures of morbidity, longer term survival and functional outcomes, which, although of great importance to patients and their families, are less well delineated and, furthermore, may provide evidence on the comparative long-term benefits of different surgical strategies and models of care.

rate was disclosed at one centre,¹ and continued scrutiny recently in the context of a proposed national reconfiguration of services.² Mandatory national audit was introduced in 1997, all specialist centres have contributed data since 2000, and centre-specific outcomes for individual procedure types have been published online since 2005.³ The UK is one of only three countries with universal

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participation in national audit of paediatric cardiac surgery, the other two being Sweden and Poland, meaning that the UK Congenital Heart Audit is a valuable resource for the evaluation of outcomes.

Outcomes were not initially included in the Safe and Sustainable Review of paediatric cardiac services,² because fair adjustment for case mix was considered too difficult to achieve. Paediatric cardiac surgery is very heterogeneous, with several thousand individual codes (International Paediatric and Congenital Cardiac Code (IPCCC)⁴) used in combinations to describe the underlying congenital heart disease (CHD); and the risk for each specific procedure varies widely.⁵ Early efforts to adjust for case mix were based on the subjective assessment of risks by panels of experts,⁶⁷ but recent empiric risk adjustment methods have been based on the analyses of records collected within audit databases.⁸ ⁹ The recent development of a UK-based risk adjustment model (PRAiS, partial risk adjustment in surgery), for the purpose of routine monitoring of outcomes by clinical teams, identified components of case mix associated with 30-day mortality for paediatric cardiac surgery including functionally univentricular heart,¹⁰ lower weight, younger age and certain underlying CHDs and procedure types.⁸¹⁰

This study aimed to evaluate trends in the raw 30-day mortality rate for UK paediatric cardiac surgery procedures over the last decade, and to explore to what extent any trend might be explained by attendant changes in the complexity of case mix.

METHODS

The officers of the Bloomsbury Research Ethics Committee (REC) deemed that the study did not require review by the REC.

The data set

The pseudoanonymised data set consisted of records of cardiac surgical operations in patients under the age of 16 years conducted in the UK before 31 December 2010. Prior to analyses being undertaken, records with missing outcome or age, and records of non-cardiac procedures from a minority of centres submitting before year 2000 and in very small numbers from adult centres, were removed.

The survival status for English and Welsh patients was independently confirmed through periodic requests to the Central Register of National Health Service (NHS) patients, as approved by the National Information and Governance Board for Health and Social Care. In Scotland, Northern Ireland and the private sector, the specialist centres verified the outcome of their own patients. Consent was requested from parents for submission of their child's data for national audit of outcomes.

The unit of analysis and outcome measure

To obviate ambiguities in assigning short-term outcomes to operations performed close together in time, we defined 30-day episodes of surgical management. The first such episode for a patient started with his or her first surgical operation and was assigned an outcome of alive or dead according to the vital status of the patient at 30 days, whether or not a reintervention occurred during the 30-day episode—this represented the main outcome measure for the study.

Case mix

Case complexity was analysed based on the following factors, all of which have been shown to be associated with 30-day mortality 8

- 1. *High risk primary CHD types*—hypoplastic left heart syndrome, pulmonary atresia with intact ventricular septum or interrupted aortic arch, defined based on a hierarchical mapping of IPCC diagnostic codes, up to six of which were available for each episode.¹⁰
- 2. *Univentricular heart*—those combinations of IPCC codes that indicated a patient with a functionally univentricular heart.¹⁰
- Age at operation—neonate (≤30 days), infant (31 days-1 year) or child (>1 year), younger age being highest risk.⁸
- 4. Weight at operation, with low weight defined as less than 2.5 kg.^{11}
- 5. Multivariate risk—one of four bands based on the estimated risk of death for an individual episode calculated using a bespoke calibration of the PRAiS risk model⁸ that excluded information on comorbidity (because of changing data quality over the study period) and era of surgery (to allow analysis of this effect). The bands used were: *band 1*—less than 1% estimated risk of death; *band 2*—cases with estimated risk between 1% and up to 3%; *band 3*—cases with between 3% and 10% estimated risk and *band 4* cases with over 10% estimated risk.
- 6. Specific procedure types—the steering committee of the congenital heart audit have developed an algorithm that links the combinations of up to six individual IPCC procedure codes in a record to 1 of 38 recognisable operations³ including generally accepted 'benchmark operations'¹² along with others. Each surgical episode in the data set was assigned to either a specific procedure according to this algorithm, or to a set of ungrouped procedures ('not a specific procedure'). Within the 38 specific procedures, a group of 10 procedures with less than 100 instances each was combined into a single group referred to as the 'low volume group'.⁸

Analysis

The number of episodes, raw mortality rate and the case mix were assessed within the study cohort using a calendar year as the unit for comparison. The year 2010 contained a truncated amount of data corresponding to around half of the cases for that calendar year, related to the date on which the data were harvested, therefore the years 2009/2010 were combined for analyses, except the count of procedures per calendar year.

The 30-day mortality rate, the 30-day mortality rate within risk bands and the prevalence of categorical aspects of case mix were explored using χ^2 test for trend by calendar year. We tabulated these analyses (table 1), reporting in the text the percentage or rate for the first and the last calendar year, with 95% confidence interval (CI) and χ^2 test for trend p value.

A secondary analysis involving specific procedure groups was performed based on two eras (2000–2004 inclusive and 2005–2010 inclusive). The low number of episodes for some procedure groups did not support analysis for each calendar year. The 30-day mortality for each specific procedure group was compared between eras based on odds ratio (OR). The relative frequency for each specific procedure group was compared between eras, and the distribution of procedures by era was reviewed qualitatively. The difference in mean age at operation was calculated, compared between eras, and tested for significance using a t test. No corrections were made for multiple hypotheses testing.

RESULTS

Of 38 597 episodes, we removed 919 (2.4%) with missing outcome (see table 1), 10 episodes involving non-cardiac procedures, 53 episodes with missing age, 930 episodes from two centres that alone submitted data prior to 2000 and 44 episodes pertaining to older children operated in non-paediatric specialist centres. The data set used for analyses consisted of 36 641 episodes corresponding to 30 041 unique patients, of whom 24 899 had 1 surgical episode and 5142 underwent 2 or more surgical episodes. Of 36 641 surgical episodes, 1626 (4.4%) involved at least one reoperation and 35 015 (95.6%) of episodes consisted of only one surgical procedure.

There was a marked increase in the number of procedure episodes per completed calendar year from 2283 in 2000 to 3939 in 2009 (p<0.01; see figure 1). The raw mortality rate fell significantly and consistently over the period of review from 4.3% (95% CI 3.5% to 5.1%) in 2000 to 2.6% (95% CI 2.2% to 3.0%) in 2009/2010 (p<0.01).

Risk bands

The proportion of patients within each risk band by calendar year is shown in figure 2 and the corresponding mortality rates are shown in figure 3. While there was an increase in case volume across all risk bands, this was least pronounced in risk band 1 (lowest risk). Within band 1, the mortality rate fell from 1.4% (95% CI 0.6% to 2.1%) in 2000 to 0.5% (95% CI 0.2% to 0.7%) in 2009/2010 with strong evidence for a trend (p<0.01). Although not statistically significant, 30-day mortality fell in band 2 from 3.2% (95% CI 1.9% to 4.5%) to 1.6%

Year	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009/2010
Number of surgery episodes	2283	2925	3386	3697	3505	3655	3802	3733	3775	3939*
Missing outcome†	227 (9%)	193 (6.2%)	61 (1.8%)	16 (0.4%)	11 (0.3%)	0	7 (0.2%)	8 (0.2%)	9 (0.2%)	138 (2.3%)
Mortality % (95% CI)	4.3 (3.6 to 5.1)	4.3 (3.6 to 5.1) 3.6 (2.9 to 4.3) 3.7 (3.3 to 4.4)	3.7 (3.3 to 4.4)	3.3 (2.7 to 3.8)	2.7 (2.2 to 3.3)	3.3 (2.7 to 3.8)	2.9 (2.4 to 3.5)	3.0 (2.5 to 3.6)	3.4 (2.8 to 3.9)	2.6 (2.2 to 3.0)
High-risk diagnoses (%)‡	152 (6.7)	202 (6.9)	227 (6.7)	278 (7.5)	263 (7.5)	305 (8.3)	363 (9.6)	376 (10.1)	367 (9.7)	556 (9.5)
Low weight (%)§	161 (8.1)	203 (7.7)	329 (10.2)	281 (8.2)	321 (9.7)	354 (10.3)	381 (10.3)	329 (9.0)	405 (11.0)	592 (10.4)
Functionally univentricular	302 (13.2)	377 (12.9)	432 (12.8)	521 (14.1)	497 (14.2)	538 (14.7)	603 (15.9)	629 (16.9)	632 (16.7)	961 (16.3)
heart (%)										
Risk band 4 (%)	139 (6.8)	166 (6.4)	190 (6.4)	215 (6.6)	214 (6.8)	213 (6.8)	258 (7.8)	256 (8.3)	222 (7.3)	272 (7.2)
Children (%)	929 (40.7)	1233 (42.2)	1458 (43.1)	1654 (44.7)	1466 (41.8)	1494 (40.9)	1553 (40.9)	1591 (42.6)	1521 (40.3)	2341 (39.8)
Infants (%)	813 (35.6)	1055 (36.1)	1166 (34.4)	1279 (34.6)	1292 (36.9)	1429 (39.0)	1447 (38.0)	1359 (36.4)	1463 (38.8)	2309 (39.2)
Neonates (%)	541 (23.7)	637 (21.8)	762 (22.5)	764 (20.7)	747 (21.3)	732 (20.1)	802 (21.1)	783 (21.0)	791 (21.0)	1230 (21.0)
*Given that the year 2010 contained a truncated amount of data, as stated in Methods, the years 2009/2010 were combined for analyses. This cell relates to 2009 only, whereas data in lower cells relate to 2009/2010.	ained a truncated	d amount of data	a, as stated in N	lethods, the yea	ars 2009/2010 w	ere combined fo	or analyses. This	cell relates to 20	009 only, wherea	s data in lower
†Records with missing outcome listed in this row are excluded from the rest of the analyses.	e listed in this rov	w are excluded	from the rest of	the analyses.						
‡Overall there were 1270 records with a missing diagnosis that were	ds with a missing	g diagnosis that	were excluded	excluded from this row of data.	data.					
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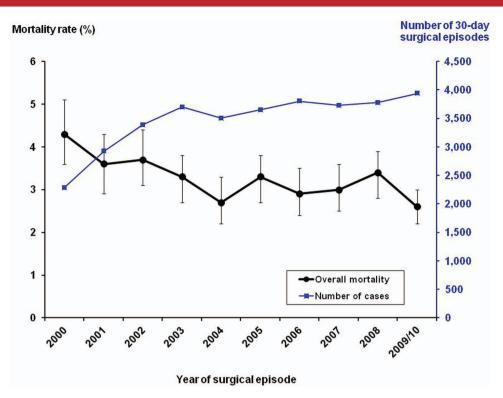


Figure 1 UK paediatric cardiac surgery mortality rate by year for all cases and total number of procedures performed between 2000 and 2009/2010. Figure shows observed annual paediatric cardiac surgery case numbers for each completed year between 2000 and 2009 (presented as a single year in this instance) and national unadjusted 30-day mortality with 95% CI by year between 2000 and 2009/2010.

(95% CI 1.1% to 2.2%; p=0.09) and in band 3 from 11.1% (95% CI 8.1% to 14.3%) to 4.5% (95% CI 3.6% to 6.0%; p=0.08). In band 4 (highest risk), the 30-day mortality rate was similar over the period of review: 10.3% (95% CI 9.5% to 15.2%) in 2000 and 12.7% (9.5% to 15.8%) in 2009/2010 (p=0.58).

Case mix

There was evidence for an overall rise in case complexity over the period of review (figure 4). The proportion of low weight babies increased from 8.1% (6.9% to 9.3%) in 2000 to 10.4% (95% CI 9.6% to 11.1%) in 2009/2010 (p=0.05); the proportion of surgical episodes in patients with functionally univentricular hearts increased from 13.2% (95% CI 11.8% to 14.6%) in 2000 to 16.3% (95% CI 15.4% to 17.3%) in 2009/2010 (p<0.01), and the proportion of surgical episodes for patients with higher risk diagnoses (hypoplastic left heart syndrome, pulmonary atresia or interrupted aortic arch) increased from 6.7% (95% CI 5.6% to 7.7%) in 2000 to 9.5% (95% CI 8.7% to 10.2%) in 2009/2010 (p<0.01). There was not a significant trend in the proportion of episodes in risk band 4, at 6.8% (95% CI 5.8% to 7.8%) in 2000 and 7.2% (95% CI 6.6% to 7.9%) in 2009/2010 (p=0.60).

The proportion of surgical episodes in neonates remained similar over the period of review, at 23.7% (95% CI 21.9% to 25.4%) in 2000 and 20.9% (19.9% to 22.0%) in 2009/2010 (p=0.49).

The proportion of episodes that were in infants increased from 35.6% (95% CI 33.7% to 37.6%) in 2000 to 39.3% (95% CI 38.0% to 40.5%) in 2009/2010 (p<0.01), with a contemporaneous fall in childhood operations from 40.7% (95% CI 38.7% to 42.7%) in 2000 to 39.8% (95% CI 38.6% to 41.1%) in 2009/2010 (p<0.01).

Specific procedure groups

Mortality rates for specific procedure groups by each 5-year time period (2005–2010 inclusive compared with 2000–2004) are shown in figure 5. We list in this section results from the analysis of 30-day mortality for specific procedure groups significant at $p \le 0.5$ (note no corrections were made for multiple hypotheses testing). The OR of 30-day mortality for the later era, period prevalence by era and difference in mean age at surgery by era, can be found in table 2.

There was evidence of significantly lower 30-day mortality in the later era for six specific procedure groups: arterial switch operation with ventricular septal defect (VSD) repair, ligation of patent ductus arteriosus (PDA), the 'no specific procedure' group, the Fontan-type operation, tetralogy of Fallot repair and isolated VSD repair. There was evidence for significantly higher 30-day mortality for only one specific operation type in the later era: the systemic to pulmonary arterial shunt.

There was evidence that definitive surgical repairs are case, with a lower age at operation in the later era, for several procedures applicable to babies and small

children: complete atrioventricular septal defect repair, VSD repair, tetralogy of Fallot repair, coarctation repair, subaortic stenosis repair and Rastelli procedure. This is in keeping with selected single centre reports, advocating the safety of earlier repair in complete atrioventricular septal defect¹³ and tetralogy of Fallot.¹⁴ Moreover, it is consistent with a decrease in the relative frequency of palliative arterial shunts in lieu of definitive repair and a younger age at operation among arterial shunt patients. Higher 30-day mortality among the residual smaller group of patients undergoing arterial shunt in the later era relates to greater complexity (mean multivariate risk increased in era 2 for shunt patients, data not shown) as has been observed in other published data.¹⁵

The increase in the relative frequency of the Norwood operation, arterial switch with VSD repair, PDA ligations (a procedure performed predominantly for premature babies) and bidirectional cavopulmonary shunt (also occurring at younger age), as shown in table 2, is consistent with a more proactive approach nationally to the treatment of small babies with more complex conditions, tying in with our finding of a greater proportion of

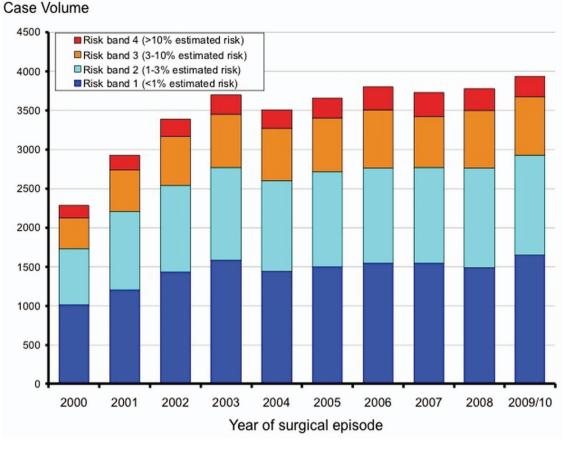


Figure 2 UK trends in paediatric cardiac surgery case volume analysed by risk band between 2000 and 2009. Figure shows observed annual paediatric cardiac surgery case numbers for each completed year between 2000 and 2009 (presented as a single year in this instance) divided by the risk band of each surgical episode. Risk band 1-less than 1% estimated risk of death; band 2-cases with estimated risk between 1% and up to 3%; band 3-cases with between 3% and 10% estimated risk and band 4-cases with over 10% estimated risk.

DISCUSSION

In the context of a large increase in the number of procedures submitted annually for audit, the raw 30-day mortality rate for paediatric cardiac surgical episodes in the UK fell from 4.3% in 2000 to 2.6% in 2009/2010, with a downward trend over this period. The drop in 30-day mortality was seen across the lower three bands of risk, which accounted for 92.9% of surgical episodes, but not in the highest risk band. Interestingly, the UK paediatric cardiac surgery case mix has become more rather than less complex over a decade of improving outcomes as reflected by the increased prevalence of functionally univentricular hearts, high-risk diagnoses and low weight at operation (<2.5 kg). This trend suggests that rather than turning away higher risk patients during an era when outcomes have been monitored more closely, conversely, a greater proportion of more complex patients were taken on in later years.

being performed earlier in life than was previously the



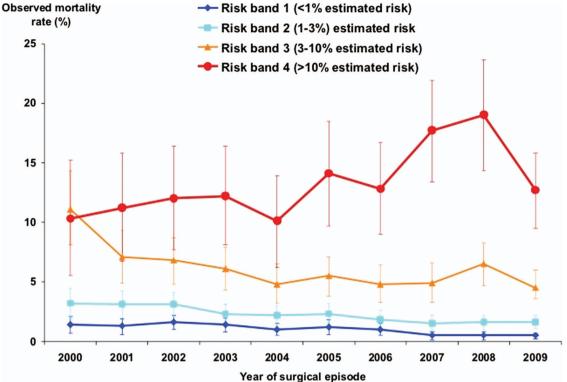


Figure 3 UK trends in paediatric cardiac surgery case mortality rate analysed by risk band between 2000 and 2009/2010. Figure shows the national unadjusted 30-day mortality with 95% CI by year between 2000 and 2009/2010 divided by the risk band of each surgical episode. Risk band 1-less than 1% estimated risk of death; band 2-cases with estimated risk between 1% and up to 3%; band 3—cases with between 3% and 10% estimated risk and band 4—cases with over 10% estimated risk.

operations at low weight. The Norwood operation fell into the highest risk band 4, and although the UK outcomes compare well with Norwood other Registry-based data,⁹ there was no improvement in band 4 outcomes over the period of review. We note that mean multivariate risk increased among risk band 4 over time (data not shown). Furthermore, we were unable to include comorbidity information in our study because of data quality issues: in the most recent data reported by the National Institute of Cardiovascular Outcomes Research (NICOR) for 2009/2012, the rate of comorbid conditions was the highest ever reported at 30%,¹⁶ and while this may represent improved capture of this element, there may also be a true increase in comorbidity over time, with such babies prevalent in risk band 4. A wider acceptance of very complex patients for surgical management may have mitigated the effects of improvements in care, which more obviously benefited other patient groups in terms of the reported improvements in outcome for lower risk patients.

The number of procedures performed per annum increased over the period of review, with the smallest proportionate increase in risk band 1 cases (see figure 2), which were relatively static in terms of annual case volume from 2003 onwards. A relatively small rise in the number of incident cases of CHD in the UK has been reported over the same era,¹⁷ therefore the increase in national case volume supports the hypothesis of a more proactive approach towards surgical treatment of CHD and greater likelihood of early survival among surgically treated patients who require serial operations over their life time.

Strengths and weaknesses of the study

The mandatory submission of data for national audit of paediatric cardiac surgery in the UK and the data quality assurance processes employed by NICOR to promote full and standardised reporting of surgical activity is a considerable strength for this study. That said, as for any study based on retrospective observational data, conclusions must be viewed in the context of limitations to data quality. As stated in the results, episodes with missing outcome (919, 2.4% of episodes in the original dataset) were removed. The distribution of missing outcome (table 1) was concentrated at the start and at the end of the period of review, which is explained by process issues in 2000-2002 and the harvest of the data before complete ascertainment of outcome could be performed for 2009/2010. Between the years 2003 and 2008, the level of missing outcome was 0% and 0.4%, and therefore unlikely to render inaccurate the reported national mortality rate between these years. As stated, due to the poor level of completeness of comorbidity data and changes in this aspect over time, we were unable to include this in the study. Given the role of NICOR in audit of centre-specific outcomes

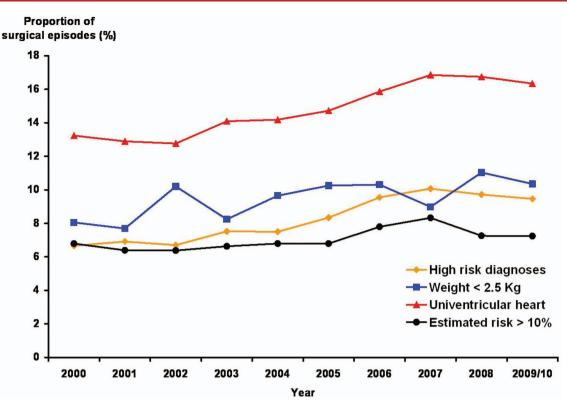


Figure 4 UK trends in selected aspects of paediatric cardiac surgery case mix between 2000 and 2009/2010. Figure shows selected aspects of the national case mix related to all paediatric cardiac surgery cases for each year between 2000 and 2009/2010 shown as a proportion with 95% CI. These are operations in patients with functionally univentricular hearts (triangle); operations performed in patients with underlying higher risk congenital heart disease types (diamond), include hypoplastic left heart syndrome, pulmonary atresia with intact septum and interrupted aortic arch; operations in babies weighing <2.5 kg (square) and cases in risk band 4 (circle).

and the study objective of evaluating national trends, the research team did not seek permission to perform analyses of outcomes within individual centres.

Study data in context

Outcomes of improved mortality in paediatric cardiac surgery, attributed to surgical techniques and intensive care practices, have been reported previously from the USA.¹⁸ The North American paediatric cardiac surgery audit database 'STS-CHSDB' recently published the discharge mortality rate for the 85 participating centres between 2005 and 2009 at 4.1% (3309 of 81 062 surgery admissions).¹⁹ We note that discharge mortality is different from 30-day mortality since it contains longer stay patients, and therefore the two are not directly comparable. The European Association for Cardiothoracic Surgery (EACTS) database currently posts 16 578 procedures in 14 501 patients for 2009, with a 4.01% 30-day mortality, which is a reduction from 4.26% 30-day mortality for 2008.²⁰ Although having wide coverage, submission of data is not mandatory and neither of these large multi-institutional databases is completely representative of national or regional outcomes. Furthermore, only a small proportion of centres submitting data to these registries are validated, whereas there are independent annual validation visits in UK centres.²

Across these studies, there are differences in how early postoperative outcomes are defined and attributed. Our study is based on 30-day status, which in comparison with discharge status has the advantage of being inured to differences in institutional discharge and referral protocols. However, with increased capability to prolong life in intensive care, survival to 30-days is arguably a less robust measure of successful early outcome than it once was. Also, it should be noted that the analysis we report is based on outcomes for 30-day surgical episodes and not at the level of each visit to theatre by a patient.

The history of paediatric cardiac surgery in the UK is such that the specialty is highly scrutinised and connected in the public mind to troubling past events.^{1 22} The results reported in this paper reflect the national early surgical outcomes over a period where the specialty has been subject to a far reaching review: the 'Safe and sustainable review of paediatric cardiac surgery'.² This process led to exploration of every aspect of paediatric cardiac care in each centre nationally, and while negative views on the safe and sustainable review process have been expressed, it may be the case that the detailed critique and suggestions for improvement by a panel of experts did contribute to improvements in quality both locally and nationally. The very low mortality rates at 30 days must shift our focus now towards measures of morbidity, longer term survival

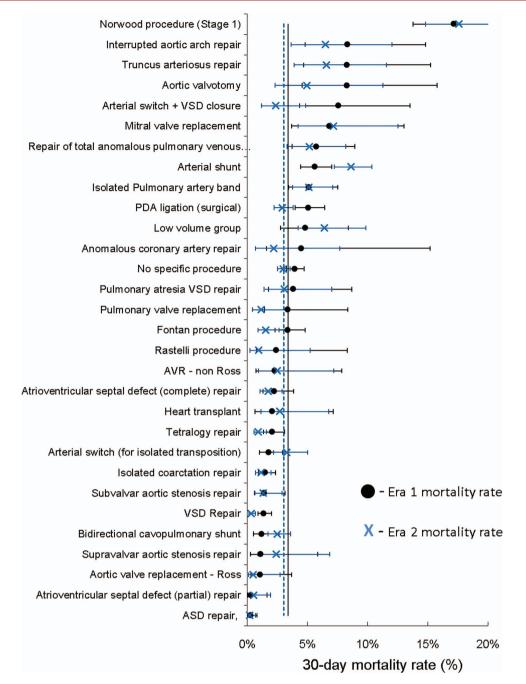


Figure 5 UK paediatric cardiac surgery 30-day mortality rates for individual specific procedures by era (2000–2004 compared with 2005–2010). Figure shows observed 30-day mortality for specific procedure groups in the first era 2000–2004 (circles) and the second era 2005–2010 (crosses) with 95% CI (bars). The vertical lines denote the mean 30-day mortality in the first era (black continuous, representing 3.4%) and the second era (blue dashed, representing 2.9%). Data are ordered in decreasing 30-day mortality for the first era 2000–2004. The low-volume procedure group (n=528, 1.4% of operations performed) includes aortic root replacement (not Ross), aortopulmonary window repair, atrioventricular septal defect and tetralogy repair, cor triatriatum repair, multiple VSD closure, Senning or Mustard procedure, tetralogy with absent pulmonary valve repair, total anomalous pulmonary venous connection repair plus arterial shunt, tricuspid valve replacement and truncus with interrupted aortic arch repair. The 'not a specific procedure' group contains all bypass and non-bypass cardiac operations that did not fall into a defined group: 6791 (18.5%) operations performed. VSD, ventricular septal defect; PDA, patent ductus arteriosus; AVR, aortic valve replacement; ASD, atrial septal defect.

outcomes (such as survival to 90 days or 1 year) and functional outcomes, which, although of great importance to patients and their families, are less well delineated, and furthermore may provide evidence on the comparative longterm benefits of different surgical strategies and models of care. The patient groups where improvements in outcome have not been observed, including babies undergoing shunts and the most complex children in risk band 4, warrant further more detailed audit, in order to establish whether further lessons may be learned.

Table 2 (Landscape): Specific procedure groups expressed in terms of the total number, the OR of 30-day mortality in the later era (2005–2010), the period prevalence as a percentage of total cases in the first (2000-2004) and second era (2005-2010), and the difference in mean age between era 1 (2000-2004) and era 2 (2005-2010)

Specific procedure (ranked in order of 30-day mortality		OR of 30-day mortality for	Period prevalence as a percentage for era 1	Period prevalence as a percentage for era 2	Mean age (years) difference:
for era 1)	Number	era 2 (95% Cl)	(95% CI)	(95% CI)	era 1 minus era 2 (95% CI)
Norwood procedure	931	1.03 (0.73 to 1.46)	2.3 (2.0 to 2.5)	2.8 (2.6 to 3.0)	0.02 (-0.02 to 0.05)
Aortic valvotomy	198	0.58 (0.18 to 1.84)	0.6 (0.5 to 0.7)	0.5 (0.4 to 0.6)	-0.63 (-1.95 to 0.69)
Mitral valve replacement	272	1.06 (0.41 to 2.71)	0.7 (0.6 to 0.9)	0.7 (0.6 to 0.9)	−1.4 (−2.6 to −0.18)
Interrupted aortic arch repair	260	0.77 (0.30 to 1.96)	0.8 (0.8 to 0.9)	0.7 (0.6 to 0.8)	0.01 (-0.23 to 0.25)
Truncus arteriosus repair	276	0.78 (0.31 to 1.96)	0.7 (0.6 to 0.8)	0.8 (0.7 to 0.9)	-0.17 (-0.44 to 0.10)
Arterial switch+VSD closure	428	0.30 (0.11 to 0.80)	0.8 (0.7 to 1.0)	1.4 (1.2 to 1.5)	0.04 (-0.15 to 0.24)
Total anomalous pulmonary veins repair	644	0.90 (0.45 to 1.78)	2.0 (1.8 to 2.2)	1.6 (1.4 to 1.8)	0.14 (-0.08 to 0.36)
Arterial shunt	2436	1.60 (1.17 to 2.20)	7.6 (7.2 to 8.0)	5.9 (5.6 to 6.2)	0.35 (0.20 to 0.50)
Isolated pulmonary artery band	1138	1.01 (0.59 to 1.74)	2.9 (2.6 to 3.1)	3.3 (3.0 to 3.5)	0.03 (-0.17 to 0.23)
PDA ligation	3012	0.56 (0.39 to 0.82)	7.7 (7.3 to 8.1)	8.6 (8.2 to 9.0)	0.27 (-0.01 to 0.62)
Anomalous coronary artery repair	137	0.48 (0.07 to 3.51)	0.3 (0.2 to 0.4)	0.4 (0.3 to 0.5)	-1.16 (-2.41 to 0.08)
Low volume group	288	1.37 (0.64 to 2.93)	1.5 (1.3 to 1.6)	1.5 (1.3 to 1.6)	0.29 (-0.52 to 1.10)
Pulmonary atresia VSD repair	296	0.80 (0.23 to 2.81)	0.8 (0.7 to 1.0)	0.8 (0.7 to 0.9)	0.71 (-0.04 to 1.46)
No specific procedure	6791	0.75 (0.58 to 0.98)	17.5 (16.9 to 18.1)	19.3 (18.8 to 19.9)	0.28 (0.69 to 0.50)
Fontan-type procedure	1610	0.45 (0.23 to 0.89)	5.2 (4.8 to 5.5)	3.8 (3.5 to 4.1)	-1.04 (-1.34 to -0.74)
Pulmonary valve replacement	381	0.34 (0.07 to 1.53)	0.8 (0.6 to 0.9)	1.3 (1.1 to 1.4)	-0.31 (-1.41 to 0.77)
Arterial switch	1393	0.51 (0.26 to 1.04)	4.0 (3.7 to 4.3)	3.6 (3.4 to 3.9)	0.03 (-0.02 to 0.08)
Aortic valve replacement	210	1.13 (0.18 to 6.90)	0.6 (0.5 to 0.7)	0.6 (0.5 to 0.7)	-0.47 (-1.50 to 0.56)
Tetralogy repair	2359	0.44 (0.21 to 0.91)	6.6 (6.2 to 7.0)	6.3 (6.0 to 6.7)	0.22 (0.09 to 0.34)
Atrioventricular septal defect (complete) repair	1357	0.78 (0.36 to 1.70)	3.5 (3.2 to 3.7)	3.9 (3.6 to 4.2)	0.25 (0.05 to 0.45)
Rastelli procedure	190	0.40 (0.04 to 4.48)	0.5 (0.4 to 0.7)	0.5 (0.4 to 0.6)	1.59 (0.76 to 2.41)
Heart transplant	528	1.34 (0.24 to 7.44)	0.6 (0.5 to 0.7)	0.7 (0.6 to 0.8)	1.32 (-0.04 to 2.69)
Bidirectional cavopulmonary shunt	1495	2.19 (0.84 to 5.74)	2.8 (2.5 to 3.0)	5.1 (4.8 to 5.4)	0.37 (0.12 to 0.62)
Isolated coarctation repair	2243	0.79 (0.38 to 1.64)	7.0 (6.6 to 7.4)	5.5 (5.2 to 5.8)	0.33 (0.07 to 0.59)
Ross operation	402	0.47 (0.04 to 5.21)	1.2 (1.1 to 1.4)	1.0 (0.8 to 1.1)	-0.57 (-1.49 to 0.36)
Subvalvar aortic stenosis repair	825	0.98 (0.30 to 3.24)	2.3 (2.1 to 2.6)	2.2 (2.0 to 2.4)	0.76 (0.17 to 1.35)
Ventricular septal defect repair	3583	0.22 (0.09 to 0.56)	10.0 (9.6 to 10.5)	9.6 (9.2 to 10.0)	0.19 (0.001 to 0.38)
Supravalvar aortic stenosis repair	220	2.26 (0.23 to 22.16)	0.6 (0.5 to 0.7)	0.6 (0.5 to 0.7)	0.98 (-0.10 to 2.07)
ASD repair	2053	0.83 (0.12 to 5.89)	5.9 (5.5 to 6.3)	5.4 (5.1 to 5.7)	0.17 (-0.15 to 0.48)
Atrioventricular septal defect (partial) repair	725	1.84 (0.17 to 20.39)	2.2 (2.0 to 2.4)	1.8 (1.6 to 2.0)	0.47 (-0.06 to 1.01)

Data highlighted in bold all have p<0.05 for the test statistic: OR, difference in proportions, differences in means. ASD, atrial septal defect; PDA, patent ductus arteriosus; VSD, ventricular septal defect.

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REFERENCES

- Aylin P, Alves B, Best N, *et al.* Comparison of UK paediatric cardiac surgical performance by analysis of routinely collected data 1984–96: was Bristol an outlier? *Lancet* 2001;358:181–7.
- 2. NHS. Safe and sustainable: childrens congenital cardiac services. NHS Specialist Services, 2011.
- CCAD. Central Cardic Audit Database: paediatric analysis home page. In: Center TI, ed. *Congenital heart disease website*. London: The Information Centre, 2011. https://nicor4.nicor.org.uk/CHD/ an_paeds.nsf/WBenchmarksYears?openview&RestrictToCategory= 2013&start=1&count=500
- 4. Franklin RC, Jacobs JP, Krogmann ON, *et al.* Nomenclature for congenital and paediatric cardiac disease: historical perspectives

and The International Pediatric and Congenital Cardiac Code. *Cardiol Young* 2008;18(Suppl 2):70–80.

- Jacobs JP, Jacobs ML, Lacour-Gayet FG, *et al.* Stratification of complexity improves the utility and accuracy of outcomes analysis in a Multi-Institutional Congenital Heart Surgery Database: application of the Risk Adjustment in Congenital Heart Surgery (RACHS-1) and Aristotle Systems in the Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database. *Pediatr Cardiol* 2009;30:1117–30.
- Jenkins KJ, Gauvreau K, Newburger JW, et al. Consensus-based method for risk adjustment for surgery for congenital heart disease. J Thorac Cardiovasc Surg 2002;123:110–18.
- J Thorac Cardiovasc Surg 2002;123:110–18.
 7. Lacour-Gayet F, Clarke D, Jacobs J, et al. The Aristotle score for congenital heart surgery. Semin Thorac Cardiovasc Surg Pediatr Card Surg Annu 2004;7:185–91.
- Crowe S, Brown KL, Pagel C, et al. Development of a diagnosisand procedure-based risk model for 30-day outcome after pediatric cardiac surgery. J Thorac Cardiovasc Surg 2013;145:1270–8.
- O'Brien SM, Clarke DR, Jacobs JP, et al. An empirically based tool for analyzing mortality associated with congenital heart surgery. *J Thorac Cardiovasc Surg* 2009;138:1139–53.
- Brown KL, Crowe S, Pagel C, *et al.* Use of diagnostic information submitted to the United Kingdom Central Cardiac Audit Database: development of categorisation and allocation algorithms. *Cardiol Young* 2013;23:491–8.
- Tabbutt S, Ghanayem N, Ravishankar C, *et al.* Risk factors for hospital morbidity and mortality after the Norwood procedure: a report from the Pediatric Heart Network Single Ventricle Reconstruction trial. *J Thorac Cardiovasc Surg* 2012;144: 882–95.
- Jacobs JP, O'Brien SM, Pasquali SK, et al. Variation in outcomes for benchmark operations: an analysis of the Society of Thoracic Surgeons Congenital Heart Surgery Database. Ann Thorac Surg 2011;92:2184–91; discussion 91–2.
- Levenbrown Y, Bhat AM, Hossain J, et al. Outcome after two-patch repair of complete common atrioventricular canal defects in patients weighing four kilograms or less. World J Pediatr Congenit Heart Surg 2012;3:288–94.
- Mimic B, Brown KL, Oswal N, *et al.* Neither age at repair nor previous palliation affects outcome in tetralogy of Fallot repair. *Eur J Cardiothorac Surg* 2014;45:92–8; discussion 99.
- McKenzie ED, Khan MS, Samayoa AX, *et al.* The Blalock-Taussig shunt revisited: a contemporary experience. *J Am Coll Surg* 2013;216:699–704; discussion 04–6.
- Pagel C, Crowe S, Brown K, et al. The benefits and risks of risk-adjustment in paediatric cardiac surgery. *Heart* 2014;100:528–9.
- 17. Townsend N, Bhatnagar P, Wickramasinghe K, *et al. Children and young people statistics*. London, UK: Foundation BH, 2013.
- Welke KF, Diggs BS, Karamlou T, *et al.* Comparison of pediatric cardiac surgical mortality rates from national administrative data to contemporary clinical standards. *Ann Thorac Surg* 2009;87:216–22; discussion 22–3.
- Jacobs JP, O'Brien SM, Pasquali SK, *et al.* Variation in outcomes for risk-stratified pediatric cardiac surgical operations: an analysis of the STS Congenital Heart Surgery Database. *Ann Thorac Surg* 2012;94:564–71; discussion 71–2.
- 20. EACTS. EACTS congenital database gold standards. In: Surgery EAfC, ed. *Congenital database gold standard reports*. Warsaw Poland: Children's Memorial Health Institute, 2013. http://www.eactscongenitaldb.org/index.php?LANG=en&level=2&struct=14_1
- Clarke DR, Breen LS, Jacobs ML, et al. Verification of data in congenital cardiac surgery. Cardiol Young 2008;18(Suppl 2): 177–87.
- Spiegelhalter D, Grigg O, Kinsman R, *et al.* Risk-adjusted sequential probability ratio tests: applications to Bristol, Shipman and adult cardiac surgery. *Int J Qual Health Care* 2003;15:7–13.