

National Congenital Heart Disease Audit Report 2010 - 2013

Annual Public Report 2010 - 2013



NICOR (National Institute for Cardiovascular Outcomes Research) is a partnership of clinicians, IT experts, statisticians, academics and managers which manages six cardiovascular clinical audits and a growing portfolio of new health technology registries, including the UK TAVI registry. NICOR analyses and disseminates information about clinical practice in order to drive up the quality of care and outcomes for patients.



The National Congenital Heart Disease Audit (NCHDA) is commissioned by the **Healthcare Quality Improvement Partnership (HQIP)** as one of the Clinical Outcome Review Programmes. HQIP's aim is to promote quality improvement and is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. The Clinical Outcome Review Programmes, which encompasses confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers and policy makers to learn from adverse events and other relevant data. The NCHDA is funded by NHS England.



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Acknowledgments

The National Congenital Heart Disease Audit is managed by the National Institute for Cardiovascular Outcomes Research (NICOR), which is part of the National Centre for Cardiovascular Prevention and Outcomes, based at University College London. The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

We would especially like to thank the contribution of all NHS Trusts, and Specialist centers in Scotland and The Republic of Ireland, UK private hospitals and the individual nurses, clinicians and audit teams who collect data and participate in the audit. Without this input the audit could not continue to produce credible analysis, or to effectively monitor and assess the standard of surgical and transcatheter cardiovascular intervention.

National Audit of Congenital Heart Disease

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1 Executive summary

1.1 Background

Congenital heart disease refers to any defect of the heart present from birth. It includes structural defects, congenital arrhythmias, and cardiomyopathies. Acquired heart disease develops after birth and examples of heart disease developed in childhood include inflammatory heart disease such as rheumatic heart disease. At least 8 in every 1,000 babies are born with a heart or circulatory condition and only a quarter of these are detected by antenatal ultrasound scans.

The National Congenital Heart Disease Audit (NCHDA) collects data from all centres undertaking congenital cardiac surgery and interventional procedures in the UK and Republic of Ireland. It is commissioned by the Healthcare Quality Improvement Partnership, clinically led by the British Congenital Cardiac Association and The Society for Cardiothoracic Surgery in Great Britain and Ireland, and managed by the National Institute for Cardiovascular Outcomes Research (NICOR).

The audit aims to improve the quality of specialist congenital care by providing reliable data on patient outcomes.

1.2 Participation

The findings are based on data submitted by 14 paediatric centres and 20 centres who only undertake procedures in adults with congenital heart disease. This covers all NHS and private paediatric and congenital heart disease procedures undertaken at centres in the UK and Republic of Ireland. Analyses are based on 22,979 paediatric and congenital heart surgery and interventions undertaken between April 1st 2010 to March 31st 2013. Data has undergone a rigorous validation process comprising site visits by a clinical data auditor and volunteer clinician and has been verified by each local hospital as being accurate.

1.3 Methodology

The audit covers all congenital cardiac surgical and interventional procedures. Paediatric cardiac procedures are defined as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years. Adult congenital cardiac procedures are defined as those performed for a cardiac defect present from birth. This does not include surgery or therapeutic catheterisation for degenerative disease such as aortic aneurysm, dissection or coronary artery bypass surgery.

The audit uses the EPCC international (European Paediatric Cardiac Code) and WHO ICD-10 codes (World Health Organization, International Classification of Diseases) and OPCS (Classification of Interventions and Procedures) 04.6 coding systems.

Data has undergone a rigorous validation process comprising site visits by a clinical data auditor and volunteer clinician and has been verified by each local hospital as being accurate.

All centre aggregated analysis was conducted using PRAiS software (version 2.2). PRAiS estimates the risk of death within 30 days of a primary surgical procedure, based on specific procedure, age, weight and the patient recorded diagnoses and comorbidities.

The audit uses two control limits: an alert limit (99.5%; red line) and a warning limit (98%; green line). The warning limit is significantly different to an alert limit as survival rates may fall below the warning limit for a number of reasons, including complexity of cases and small numbers. The statistical methods used mean that there is a 1 in 40 chance that a hospital will reach the warning limit purely by chance.

1.4 Key findings

- Survival at 30-days after each of the 57 surgical and transcatheter cardiovascular interventions most frequently undertaken to treat congenital heart disease in children, young people and adults continues to be within the appropriate limits and not below the red alert limit.
- Leeds General Infirmary was below the warning limit for the aggregate analysis of all paediatric surgical procedures. LGI and Bristol Royal Hospital for Children were below the warning limit (98% control limit; green line) for a single procedure. Both hospitals have been contacted by NICOR and the relevant professional societies, and responses are available on the NCHDA portal. In relation to the aggregate analysis, NICOR has validated the 2013/14 data and undertaken a preliminary analyses. The results indicate that 2013/14 30 day survival rates for paediatric surgery are now above the warning limit and within the appropriate range. A supplementary report of this work is also available on the NCHDA portal.
https://nicor5.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument
- Antenatal diagnosis of congenital heart disease has gradually improved over the past 7 years. In 2012/13, over 40% of infants who required a procedure to treat a congenital heart malformation were diagnosed through antenatal screening, compared to less than a quarter of cases in 2003/4.

2 Introduction

2.1. Congenital Heart Disease

Congenital heart disease refers to any defect of the heart present from birth. It includes structural defects, congenital arrhythmias, and cardiomyopathies. Acquired heart disease develops after birth and examples of heart disease developed in childhood include inflammatory heart disease such as rheumatic heart disease. At least 8 in every 1,000 babies are born with a heart or circulatory condition and only a quarter of these are detected by antenatal ultrasound scans. The diagnosis and treatment of complex heart defects has greatly improved over the past few decades. As a result, almost all children who have complex heart defects survive to adulthood.

Congenital heart disease is relatively rare and requires specialist clinicians who have experience in treating paediatric and adult patients. In the UK, the majority of major procedures are undertaken at dedicated congenital heart disease centres.

2.2. The role of the audit

The National Congenital Heart Disease Audit (NCHDA) aims to improve the quality of specialist congenital care by providing reliable data on patient outcomes. The audit has been reporting risk-adjusted outcomes for procedures for over a decade. Results are used for a wide range of quality improvement initiatives, including local and national audit, service review, development of national quality indicators and outcomes based research.

The audit collects data from all centres undertaking major congenital heart disease procedures England, Scotland, Wales and Republic of Ireland. Participation in the audit is now mandatory for all centres in England as set out in the NHS contract. Section 26.1 (26.1.2) states that the provider must “participate in the national clinical audits within the National Clinical Audit and Patient Outcomes Programme (NCAPOP) relevant to the Services.”

2.3. Organisation of the audit

The NCHDA is managed by the National Institute for Cardiovascular Outcomes Research (NICOR), which is part of the University College London. Clinical leadership is provided by representatives of the British Congenital Cardiac Association and the Society for Cardiothoracic Surgery in Great Britain and Ireland. The National Audit of Congenital Heart Disease is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

NICOR’s mission is to provide accurate data on cardiovascular outcomes for the public, healthcare providers and the medical profession.

2.4. Aim of this report

This report describes the following findings:

- Centre aggregated data 2010-13: Overall survival at 30-days after paediatric heart surgery.
- Specific procedure data 2010-13: Survival at 30-days for each of the 57 surgical and transcatheter cardiovascular interventions both in children and adults.
- Rates of antenatal diagnosis of congenital heart disease for infants who undergo a procedure.

3 Methods

3.1. Participation

The NCHDA annual audit period is from April 1st to March 31st and the deadline for submitting 2012/13 data was May 31st 2013. The findings are based on data submitted by 14 paediatric centres and 20 adult centres who only undertake procedures in adults with congenital heart disease (Figure 1).

Fig 1. Centres undertaking major congenital cardiac procedures between 2010 and 2013

Hospital	Paediatric/Adult
Liverpool, Alder Hey Hospital	Paediatric and Adult
Manchester, BMI Alexandra Hospital	Adult
Basildon, Essex Cardiothoracic Centre	Adult
Birmingham Children's Hospital	Paediatric and Adult
Liverpool Heart and Chest Hospital	Adult
Bristol Royal Hospital For Children and Bristol Royal Infirmary	Paediatric and Adult
Nottingham City Hospital	Adult
Newcastle, Freeman Hospital	Paediatric and Adult
London, St George's Hospital	Adult
Glasgow, Golden Jubilee National Hospital	Adult
London, Great Ormond Street Hospital for Children	Paediatric and Adult
Leicester, Glenfield Hospital	Paediatric and Adult
London, Evelina Children's Hospital	Paediatric and Adult
London, Hammersmith Hospital	Adult
London, Harley Street Clinic	Paediatric and Adult
London, King's College Hospital	Adult
Leeds General Infirmary	Paediatric and Adult
Swansea, Morriston Hospital	Adult
Manchester Royal Infirmary	Adult
London, New Cross Hospital	Adult
Sheffield, Northern General Hospital	Adult
London, Royal Brompton Hospital	Paediatric and Adult
Dublin, Our Lady's Children's Hospital	Paediatric and Adult
Birmingham, Queen Elizabeth Hospital	Adult
Oxford, John Radcliffe Hospital	Adult
Glasgow, Royal Hospital for Sick Children	Paediatric and Adult
Brighton, Royal Sussex County Hospital	Adult
Belfast, Royal Victoria Hospital	Paediatric and Adult
Southampton, Wessex Cardiothoracic Centre	Paediatric and Adult
London, St Thomas' Hospital	Adult
Stoke, University Hospital of North Staffordshire	Adult
London, The Heart Hospital (University College Hospital)	Adult
Cardiff, University Hospital of Wales	Adult
Blackpool Victoria Hospital	Adult

3.2. Scope

Paediatric cardiac surgical or interventional procedures are defined as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years.

Adult congenital cardiac procedures are defined as those performed for a cardiac defect present from birth. This does not include surgery or therapeutic catheterisation for degenerative disease such as aortic aneurysm or dissection or coronary artery bypass surgery. The inclusion criteria for the analysis is provided in Figure 2.

Fig 2. Analyses inclusion criteria

Analyses	Financial year	Age group	Inclusion criteria
30 day paediatric cardiac surgery	2010/13	16 years and under	All cardiac surgical procedures
30 day specific procedures	2010/13	All age groups	All surgical and transcatheter cardiovascular

3.3. Coding

The audit uses the European Paediatric Cardiac Code, World Health Organization ICD-10 codes and OPCS 4.6 coding systems. A full list of the mapped codes is available via the NCHDA portal.

3.4. Data quality

Data is validated through data validation visits and death validation procedures. In brief, all centres who submit ten or more cases (therapeutic surgery and/or catheter procedures) to the National Congenital Heart Disease Audit qualify for a validation visit. The hospital records of 20 congenital patients are randomly selected to be reviewed. The data that the centre submitted to NICOR for these 20 patients is then checked against their hospital notes. As part of the feedback to the site, the site will get a quality score (called the Data Quality Indicator) on the case note validation. The Data Quality Indicator (DQI) is a measure of the accuracy and completeness of data entry (across four domains: demographics, pre-procedure, procedure and outcome) into the NICOR outcomes software when comparing to actual patient records during a site validation visit. Typically, NICOR would expect the DQI to be great than 90%.

3.5. Antenatal diagnosis

Since 2003, the NCHDA collects data on whether the heart abnormality was detected antenatally. The antenatal results are based on data submitted between 2003/4 to 2012/13. Analysis includes all patients under 12 months who undergo surgical and transcatheter procedures excluding patent ductus, patent foramen ovale or atrial septal defect, as these conditions are not diagnosed antenatally.

3.6. Statistical methodology

3.6.1. Small numbers

Due to the relatively small number of cases, the report provides composite 3 year results for data submitted between April 1st 2010 and March 31st 2013.

3.6.2. Risk adjustment

All centre aggregated analysis was conducted using Partial Risk Adjustment in Surgery (PRAiS) software (version 2.2). PRAiS estimates the risk of death within 30 days of a primary surgical procedure, based on specific procedure, age, weight and the patient recorded diagnoses and comorbidities. The PRAiS model can only be applied to paediatric cardiac surgery and has not been validated for use in an adult congenital population. The PRAiS model has been used to reanalyse the 2009-12 aggregate performance following the initial analysis undertaken in April 2013. The updated 2009/12 aggregate analysis is available on the NCHDA portal.

More information on the PRAiS model is available via the UCL Clinical Operational Research Unit: <http://www.ucl.ac.uk/operational-research/AnalysisTools/PRAiS>

3.6.3. Control limits

The audit uses two statistical control limits for the individual procedure analyses (note, these percentages are not related to actual survival figures): a warning limit (98%) and an alert limit (99.5%). If a unit is above both limits then their performance is not statistically different from the national average. The warning limit is significantly different to an alert limit as survival rates for a specific procedure may fall below the warning limit for a number of reasons, including complexity of cases and small numbers. The statistical methods used mean that an average centre has a 1 in 40 chance of reaching the 'Alert' limit and 1 in 1000 chance of 'Alarm' limit by chance.

With respect to the PRAiS mediated analysis, these limits are known as Prediction Limits as they are driven by the risk model and a set of statistical assumptions, as opposed to observed raw data, and are therefore centred on the risk adjusted predicted outcome. For the PRAiS mediated aggregate analysis a different set of control limits is used following Department of Health guidelines: 97.5% prediction limits (2 standard deviation) and 99.9% (3 standard deviation). As there are only 14 centres in the paediatric cardiac analysis this means that there is a 25.5% risk of being beyond the warning limit and 1.35% chance of being beyond the alert limit by chance (false outlier).

4 Results

4.1. Number of procedures

Centres submitted data on 22,979 specific procedures between 2010 and 2013. Of these, 16,291 were paediatric cases and 6,688 adult cases. A more detailed breakdown by centre and age group is available on the NCHDA portal https://nicor5.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument

The antenatal diagnosis is based on 25,051 procedures undertaken between 2002/03 and 2012/2013.

4.2. Data quality

Figure 3 provides the data quality scores at each centre for both surgical and catheter procedures. Nearly all centres had data quality scores of 90% and above. The exceptions were University Hospital of North Staffordshire, Nottingham City Hospital, Kings College Hospital, University Hospital of Wales and Blackpool Victoria Hospital. All centres have received detailed feedback including recommendations on how to improve data quality. In addition, NICOR will be launching a Minimum Data Standard which all centres will be required to meet. The full Data Quality reports are available via the NCHDA portal.

Fig. 3 DQI Scores for all centres 2012/13

Hospital	DQI% for 09/10 data based on the 20 case note review				DQI% for 10/11 data based on the 20 case note review				DQI% for 11/12 data based on the 20 case note review				DQI% for 12/13 data based on the 20 case note review			
	Overall DQI %	DQI for Surgery case notes seen	DQI for Catheter Procedure case notes seen		Overall DQI %	DQI for Surgery case notes seen	DQI for Catheter Procedure case notes seen		Overall DQI %	DQI for Surgery case notes seen	DQI for Catheter Procedure case notes seen		Overall DQI %	DQI for Surgery case notes seen	DQI for Catheter Procedure case notes seen	
Liverpool, Alder Hey Hospital	93.25	91	96		96.75	97.75	95.5		95	94.25	96.25		96	96	92.75	
Manchester, BMI Alexandra Hospital	-	-	-		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures	
Basildon, Essex Cardiothoracic Centre	71	n/a	71		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures	
Birmingham Children's Hospital	95.75	94	98.25		96	94.5	98.75		95	95.75	94.25		98	98	98	
Liverpool Heart and Chest Hospital	87.75	n/a	87.75		94.75	n/a	94.75		91	n/a	n/a		97.5	n/a	97.5	
Bristol Royal Hospital for Children	95.25	91.75	96.75		95.25	92	98.25		95	91	96.25		91.75	87	96.5	
Nottingham City Hospital	74	92.25	69		67.75	n/a	67.75		69.5*	n/a	n/a		68.75	n/a	68.75	
Newcastle, Freeman Hospital	95.5	96.75	93.25		96	97.75	95.6		95.5	93.25	99		98	97	99	
London, St George's Hospital	91.5				96	n/a	96		90.5	n/a	90.5		90.75	90	91	
Glasgow, Golden Jubilee National Hospital	Validation visits began with 10/11 data				90.25	90	92.5		95	96	91.5		94	93	97.75	
London, Great Ormond Street Hospital for Children	96	94.5	99.5		97.75	98.5	97		98	98	97.5		99	98.25	98	
Leicester, Glenfield Hospital	93	95.75	91.25		94	97.75	89.5		93.25	94.75	91.75		94	95.75	90	
London, Evelina Children's Hospital	98	97.5	99.25		96	96.75	98.5		97.5	97	98.75		97	97.5	96.5	
London, Hammersmith Hospital	78.75	n/a	78.75		83	n/a	83		93.75	n/a	93.75		90	n/a	90	
London, Harley Street Clinic	94.5	95	92		97	97.5	95		94.75	93.75	98		95	94.75	96	
London, King's College Hospital	73.75	n/a	73.75		80	n/a	80		83.75	n/a	83.75		85%	n/a	85	
Leeds General Infirmary	92.5	88	98.75		95.25	95	96.25		93.5	92	95.75		94.75	94.25	96	
Swansea, Morriston Hospital	-	-	-		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures	
Manchester Royal Infirmary	93	n/a	93		92.75	92	94.75		89.25	87.75	92.25		93.5	93.75	93	
London, New Cross Hospital	-	-	-		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures	
Sheffield, Northern General Hospital	85*	n/a	85		93.25*	94.5	91.25		96.25*	98	94		94*	94.75	93.25	
London, Royal Brompton Hospital	98.25	97.25	97.5		97.75	97.75	98		99	99.75	98.25		97	97.86	96.43	
Dublin, Our Lady's Children's Hospital	Validation visits began with 11/12 data				Validation visits began with 11/12 data				92.75	92.5	92.75		95.5	97	94	
Birmingham, Queen Elizabeth Hospital	88.25	n/a	88.25		92.25	87	100		92	n/a	92		90	89	90	
Oxford, John Radcliffe Hospital	97.5	98.75	97.25		94	89	95.5		93.25	95.25	87.25		92.5	n/a	92.5	
Glasgow, Royal Hospital for Sick Children	96	95.25	95.5		94	95	92		95.75	96	97		98.5	99	99	
Brighton, Royal Sussex County Hospital	94	n/a	94		90.5	n/a	90.5		89.5	n/a	89.5		90.5	n/a	n/a	
Belfast, Royal Victoria Hospital	97.5	98.25	98		99	99	99		97	97.5	96.25		98.2	98.1	98.5	
Southampton, University Hospital	96.5	97.75	96.25		94	93.5	95.75		99	98.75	99.75		96.5	98.75	99.75	
London, St Thomas' Hospital	99	n/a	99		96	96.75	98.5		97.5	97	98.75		97.75	n/a	97.75	
Stoke, University Hospital of North Staffordshire	85.25	n/a	85.25		77.5	n/a	77.5		83	n/a	83		82.5	n/a	n/a	
London, The Heart Hospital (University College Hospital)	93.25	93.25	n/a		96	96	n/a		94.75	94.75	94.75		94.25	96.5	93.5	
Cardiff, University Hospital of Wales	95	94.25	96.25		94	81	96.25		86.75	77	93.25		82.5	72.5	87.25	
Blackpool Victoria Hospital	-	-	-		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures		Not visited - insufficient procedures	Not visited - insufficient procedures	Not visited - insufficient procedures	

*less than 20 case notes seen

4.4. Paediatric cardiac surgical procedures: 30 day risk adjusted survival rates for all centres

Figure 4 and Figure 5 show the number of surgical episodes, 30 day survival rates and an actual versus predicted survival ratio. The results show that all of the hospitals were above the statistical alert limit of 99.9% for 30 day survival rates. Leeds General Infirmary was below the statistical 97.5% warning limit which means that survival rates at this center were lower than predicted.

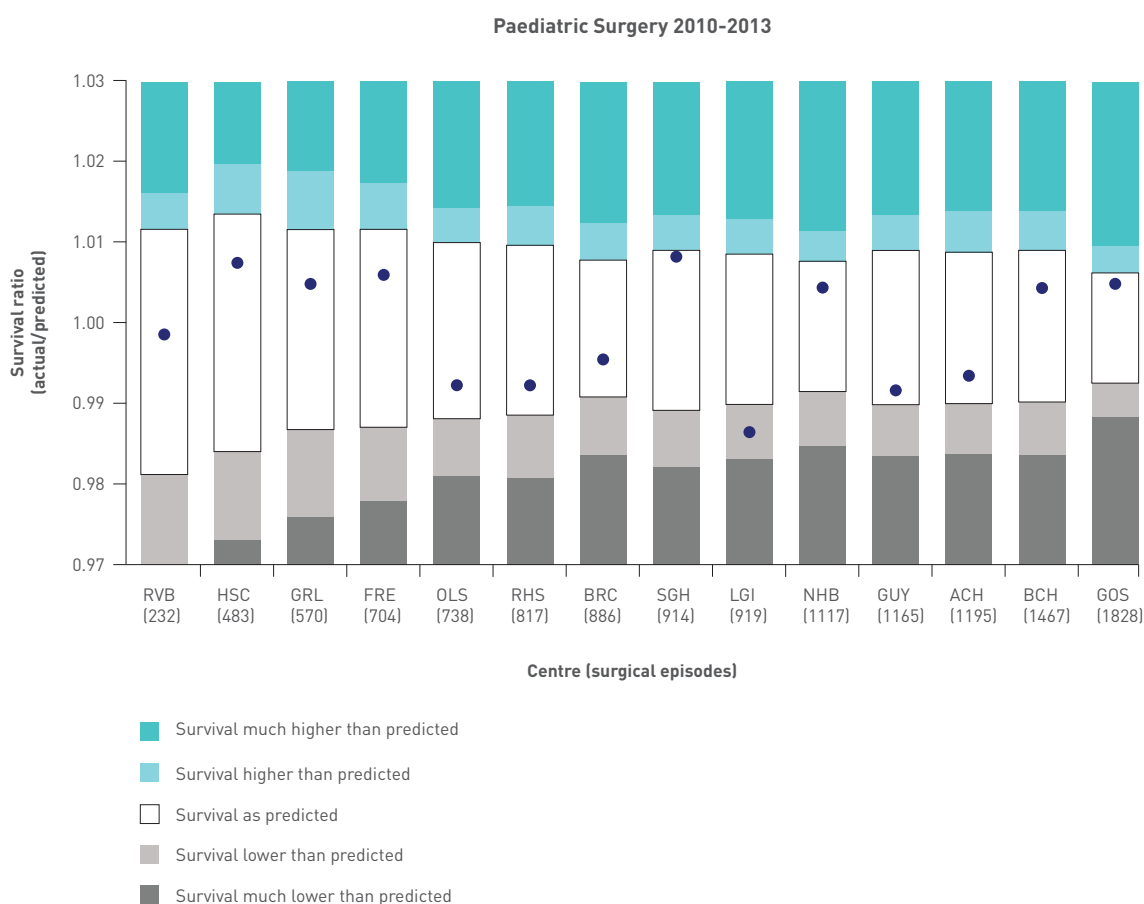
In response NICOR has validated the 2013/14 Leeds General Infirmary data and undertaken a preliminary analysis. The results indicate that during this more recent period, 30 day survival rates for paediatric cardiovascular surgery are now above the warning limit and within the appropriate range. A supplementary report of these additional results are available on the NCHDA portal.

Actual unadjusted raw survival was above 96% for all units. This is also true for adult patients whose outcomes are detailed on the NCHDA web Portal. Note that similar overall aggregate figures for adults with congenital heart disease are not possible as no risk adjustment model currently exists for these patients.

Fig 4. Surgical episodes and actual and predicted survival rates for each UK specialist centres

Code	Unit	Surgical Episodes	Actual Survival	Predicted Survival	Actual/ Predicted Survival Ratio
RVB	Belfast, Royal Victoria Hospital	232	98.3%	98.4%	0.999
HSC	London, Harley Street Clinic	483	97.9%	97.2%	1.007
GRL	Leicester, Glenfield Hospital	570	97.9%	97.4%	1.005
FRE	Newcastle, Freeman Hospital	704	97.7%	97.1%	1.006
OLS	Dublin, Our Lady's Children's Hospital	738	97.0%	97.8%	0.992
RHS	Glasgow, Royal Hospital for Sick Children	817	96.8%	97.6%	0.992
BRC	Bristol Royal Hospital For Children	886	97.6%	98.1%	0.995
SGH	Southampton, Wessex Cardiothoracic Centre	914	98.5%	97.7%	1.008
LGI	Leeds General Infirmary	919	96.5%	97.8%	0.987
NHB	London, Royal Brompton Hospital	1117	98.4%	98.0%	1.004
GUY	London, Evelina Children's Hospital	1165	96.4%	97.2%	0.992
ACH	Liverpool, Alder Hey Hospital	1195	96.7%	97.3%	0.993
BCH	Birmingham Children's Hospital	1467	97.0%	96.6%	1.004
GOS	London, Great Ormond Street Hospital for Children	1828	98.2%	97.8%	1.005

Fig 5. Outcome analysis: Paediatric Cardiac Surgery in the UK between 2010 and 2013



4.5. Specific procedures 30 day survival rates (2010/13)

Thirty-day survival is analysed in 57 major surgical and transcatheter cardiovascular interventions undertaken to treat congenital heart disease. In all hospitals 30 day survival was above the alert limit for all procedures in children and adults. In two hospitals survival was below the warning limit for one procedure. Bristol Royal Hospital for Children was below the warning limit (98%; green line) for the arterial shunt procedure, and Leeds General Infirmary was below the warning limit (98%; green line) for the arterial switch operation. All 30-day survival for all other procedures in both hospitals was within appropriate parameters.

The results of all 57 procedures for children and adults are available on the NCHDA public portal: https://nicor5.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument

4.6. Antenatal diagnosis of congenital heart disease

4.6.1. Diagnosis rates

Figure 6 and Figure 7 show the trend in the whole of the UK towards improved antenatal diagnosis over the past seven (financial) years. In 2003/04, less than 25% of cases of infants undergoing a procedure were diagnosed antenatally, compared to more than 40% in 2012/13. The value shown is the percentage of eligible cases that were successfully diagnosed antenatally. Please note this is not the same as the overall antenatal detection rate as it does not take into account deaths during pregnancy or termination of pregnancy, or perinatal deaths or deaths in infancy in infants with congenital heart malformations who did not have a procedure.

Fig 6. Percentage of eligible cases that were successfully diagnosed antenatally

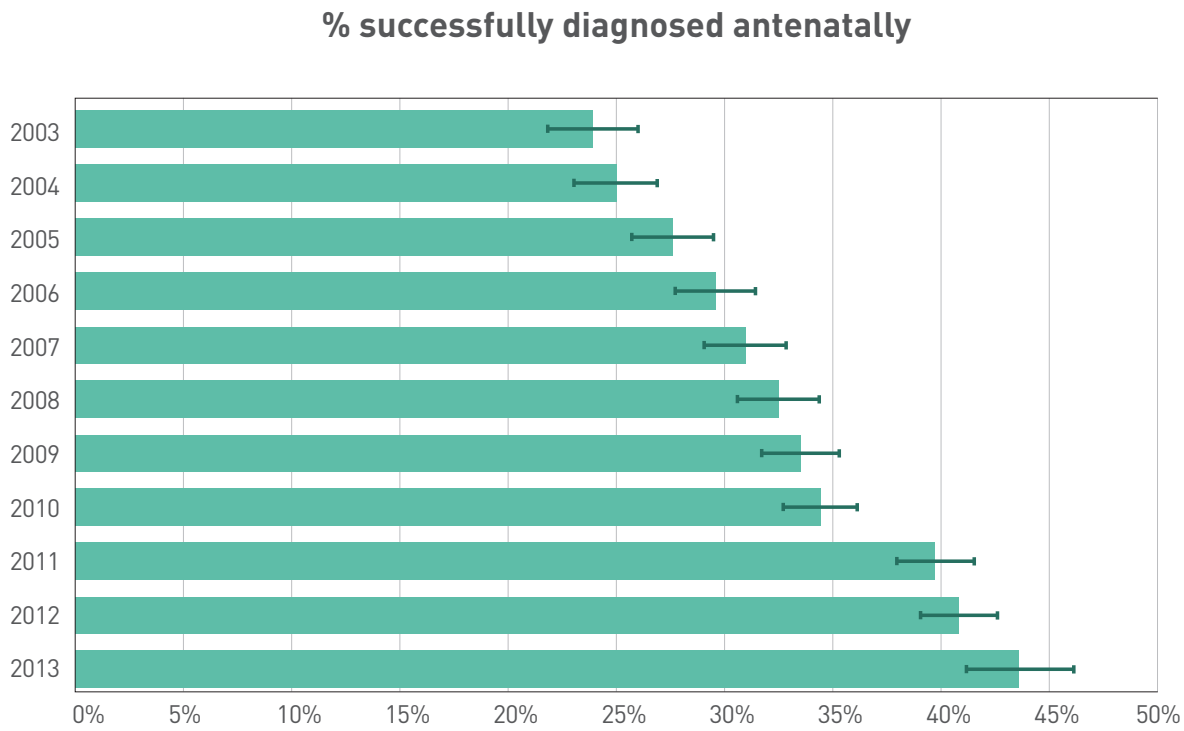


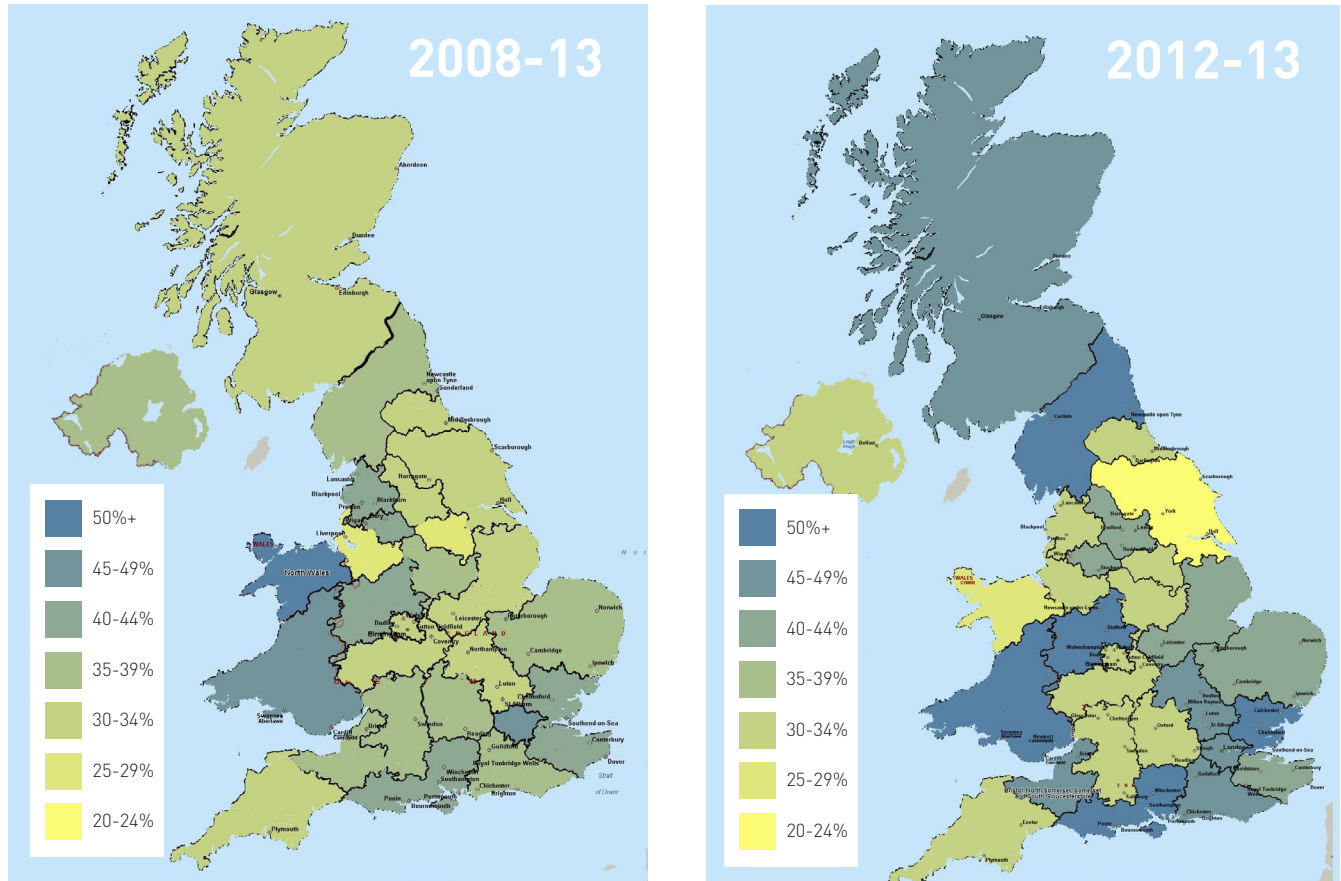
Fig 7. UK national detection rates

	2009-10	2010-11	2011-12	2012-13
England	35%	38%	40%	42%
Ireland	Data not available for this period	22%	37%	33%
N Ireland	40%	32%	36%	34%
Scotland	10%	8%	26%	22%
Wales	34%	30%	37%	47%

4.6.2. National detection rates

The percentage of infants who required treatment and were antenatally diagnosed varies across the UK (Figure 8).

Fig 8. Regional differences in percentage of infants who required treatment and were antenatally diagnosed



5 Conclusions

- The 2010/13 aggregate analysis of all paediatric cardiac surgical procedures shows that no centre crossed the alert limit. Two hospitals reached the warning limit (98%; green line) for a single procedure and one hospital for the aggregate analysis of all procedures. NICOR has alerted the medical director and the relevant professional societies, in line with Department of Health guidance on managing outliers.² It should be noted that causes of divergence include complex heart lesions (case mix) and/or comorbid factors not fully adjusted for by the risk model, intrinsic biological variability in individual patients (genetic factors), and true under-performance for a variety of reasons which may be attributable to an individual surgeon or the team looking after the patient. In relation to the specific procedure results, both hospitals have provided a formal response that is available on the NCHDA portal. In relation to the aggregate analysis, Leeds General Infirmary has undertaken an internal investigation and had a comprehensive external review. NICOR has validated the 2013/14 data and undertaken a preliminary analyse. The results indicate that risk adjusted 2013/14 30 day survival rates for paediatric surgery are now above the warning limit and within the appropriate range. A supplementary report of this work is also available on the NCHDA portal.
- Antenatal diagnosis of congenital heart disease has improved in recent years although this is not consistent across the UK. It is important to note that the results are based only on patients that undergo treatment post delivery. It does not include death during pregnancy or perinatal death, or where the condition is less severe and does not require treatment in the first 12 months or where a decision is made not to intervene due to the complexity of the heart abnormality or associated comorbidities. NHS England is undertaking a review of Congenital Heart Disease Services. One of the review's objectives is to improve antenatal and neonatal detection rates of congenital heart disease. The audit plans to support this work by expanding the audit dataset to include basic maternal details, foetal diagnosis and outcome. Alongside this work, Public Health England intends to develop a national register of congenital anomalies by April 2015.
- The limitations of the data relate to timeliness and case ascertainment of adult congenital heart disease procedures:
 - » **Timeliness:** Until recently it has taken a year to check the quality of data in all hospitals. Visits are now streamlined to larger centres and are on track to complete within 6 months and report within 12 months. By 2016, NICOR aim to publish results within 6 months of the audit deadline.
 - » **Improving case ascertainment:** Some adult congenital cases treated at non-specialist centres are not always submitted to the audit. At the moment, the only way we can be confident that all cases are submitted to the audit is by visiting hospitals and checking theatre and catheter lab log books. NICOR are looking at existing information sources, such as Hospital Episode Statistics (<http://www.hscic.gov.uk/hes>) as an alternative method for case ascertainment and for checking data.

References

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