

**National Congenital  
Heart Disease Audit  
Report 2011-2014**



**NICOR** (National Institute for Cardiovascular Outcomes Research) is a research partnership of clinicians, IT experts, statisticians, academics and managers which manages six cardiovascular clinical audits and a growing portfolio of new health technologies, 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. HQIPs 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's by systematically enabling clinicians, managers and policy makers to learn from adverse events and adverse data.

The NCHDA is funded by NHS England.



Founded in 1826, **UCL** (University College London) was the first English university established after Oxford and Cambridge, the first to admit students regardless of race, class, religion or gender, and the first to provide systematic teaching of law, architecture and medicine. It is amongst the world's top universities, as reflected by performance in a range of international rankings and tables. UCL currently has almost 29,000 students from 150 countries and in the region of 10,000 employees. Its annual income is over £900 million.

## 1. Prelude

### 1.1 Acknowledgements

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 Patients Outcomes Programme (NCAPOP).

The strategic direction and development of the audit is determined by the Audit Steering Committee. This includes major stakeholders in the audit, including congenital cardiac surgeons and cardiologists, the professional societies and patient group representatives.

We would especially like to thank the contribution of all NHS Trusts and specialist centres in Scotland, Northern Ireland and the Republic of Ireland, UK private hospitals and the individual nurses, clinicians and clinical 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 care in Great Britain and Ireland, providing quality assurance of outcomes to patients, their families and all stakeholders.

### 1.2 Authors

This report was produced by:

Rodney Franklin	NICOR Clinical Lead for Congenital Heart Disease
David Cunningham	Senior Strategist, NICOR
Anthony Bradley	Project Manager, NICOR
Linda Chadburn	Audit and Research Manager, NICOR
Lin Denne	NCHDA Clinical Data Auditor, NICOR

### 1.3 Contact Details

This report is available online at

[https://nicor5.nicor.org.uk/chd/an\\_paeds.nsf/vwContent/home?Opendocument](https://nicor5.nicor.org.uk/chd/an_paeds.nsf/vwContent/home?Opendocument)

For further information or queries please contact the following:

National Congenital Heart Disease Audit (NCHDA)  
National Institute for Cardiovascular Outcomes Research (NICOR)  
Institute of Cardiovascular Science, University College London, 3<sup>rd</sup> Floor, 170 Tottenham Court Road,  
London, W1T 7HA

Tel: 020 3108 3926 e-mail: [t.whittaker@ucl.ac.uk](mailto:t.whittaker@ucl.ac.uk)

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## 2. Executive Summary

The National Congenital Heart Disease Audit (NCHDA) collects data from all centres undertaking congenital cardiac surgery and interventional procedures in the United Kingdom 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.

The findings are based on data submitted by combined 14 paediatric and adult 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 31,511 paediatric and congenital heart surgery and interventions undertaken between April 1st 2011 and March 31st 2014. 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.

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.

Risk adjustment is a crucial part of reporting the results of procedures on children and adults born with congenital heart malformations, due to the large number of different malformations, singly and in combination, that may be present, and the corresponding large number of possible therapeutic procedures used to treat the condition. The NCHDA therefore reports the results of 56 different procedures and uses specifically designed and validated software to report risk adjusted whole centre outcomes, known as Partial Risk Adjustment in Surgery (PRAiS). PRAiS estimates the risk of death within 30 days of a primary surgical procedure, based on the specific procedure, age, weight and the patient's recorded diagnoses and comorbidities.

The audit uses two statistical control limits for its analyses (note, these percentages are not related to actual survival figures): a warning limit and an alert limit. 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 the complexity of individual cases and small numbers.

### Key Findings

- In order for us to provide a true picture of care provided we rely on high quality data from participating units to analyse and compile this report; and it is gratifying to note that the quality of data received continues to improve, although some units need to address specific field deficits going forward.
- Using the risk adjustment PRAiS model over the period 2011 to 2014, we are pleased to report that no hospital had death rates higher than predicted, taking into account each the different types of operation performed at an individual centre (casemix).
- Survival at 30-days after each of the 56 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.
- For the 56 specific procedures used as a basis of inter-unit comparison, there was one warning level outliers for paediatric cardiac surgery at a single centre and none for paediatric intervention, adult congenital heart disease (ACHD) surgery and ACHD intervention. The hospital concerned has been

contacted by NICOR and the relevant professional societies, and the centre's response is available on the NCHDA portal.

- Analysis of the 30 day post procedural outcomes for all hospitals shows an upward trend in survival in the most recent 18 months. The overall 30 day survival for all congenital heart disease procedures is extremely high and indeed one of the highest reported anywhere in the world.
- Antenatal diagnosis of congenital heart disease has gradually improved over the past 8 years. In 2013/14, approaching 45% of infants who required a procedure to treat a congenital heart malformation in the first year of life were diagnosed through antenatal screening, compared to less than a quarter of cases in 2003/4.

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### 3. Introduction

The National Congenital Heart Disease Audit (NCHDA) collects data from all centres undertaking congenital cardiac surgery and interventional procedures in Great Britain 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). Participation in the audit is mandatory for all centres in the UK, as set out in the NHS contract, Section 26.1 (26.1.2), which 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.” All specialist paediatric and adult congenital heart centres submit data to the audit. However, the NCHDA Steering Committee is aware that a few centres undertaking procedures for adults with non-complex congenital heart disease do not submit their data to the NCHDA, mostly preferring to submit only to the National Adult Cardiac Surgery Audit at NICOR. Work is underway to ensure these cases are captured in the national audit.

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

Congenital heart disease refers to any defect of the heart present from birth. It includes structural defects, congenital arrhythmias and cardiomyopathies. At least eight in every 1,000 babies are born with a heart or circulatory malformation, although only a quarter to a third 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 heart malformations survive to adulthood. Acquired heart disease develops after birth and may present in childhood. Examples include inflammatory heart disease such as myocarditis or rheumatic heart disease, as well as most arrhythmias.

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

### 4. Aim and Objectives of the audit

The NCHDA aims to improve the quality of specialist congenital heart disease care by providing reliable and timely data on patient outcomes and has been reporting outcomes for surgical and interventional procedures for well over a decade.

The key objectives of the audit and this report include:

- To collect data from all centres in England, Scotland, Wales, Northern Ireland and Republic of Ireland which provide specialist congenital cardiac care.
- To report centre aggregated data for 2011-14: overall risk-adjusted survival at 30-days after a paediatric or congenital heart surgical procedure in patients under 16 years of age.
- To report specific procedure data for 2011-14: survival at 30-days for each of the 56 surgical and transcatheter cardiovascular interventions both in children and adults.
- To report overall and region specific antenatal detection rates for the diagnosis of congenital heart disease in those requiring an intervention in infancy.
- To provide results which can be used locally for a range of quality improvement initiatives.

## 5. Methodology

### 5.1 Participation

The findings are based on data submitted by 14 paediatric centres and 20 adult centres in the United Kingdom and Republic of Ireland. Analyses are based on 31,511 paediatric and congenital heart surgery and interventions undertaken between April 1<sup>st</sup> 2011 and 31<sup>st</sup> March 2014. Adult congenital cardiac procedures are defined as those performed for a cardiac defect malformation present from birth. This does not include surgery or therapeutic catheterisation for degenerative disease such as aortic aneurysm or dissection or mitral valve surgery.

The NCHDA annual audit period is from April 1<sup>st</sup> to March 31<sup>st</sup> and the deadline for submitting 2013/14 data was May 31<sup>st</sup> 2014. The findings are based on data submitted by 14 specialist paediatric centres and 20 adult congenital centres. Centres are listed in Table one.

<b>Hospital</b>	<b>Code</b>	<b>Paediatric/Adult</b>
Belfast, Royal Victoria Hospital	RVB	Paediatric/Adult
Birmingham Children's Hospital	BCH	Paediatric/Adult
Bristol Royal Hospital For Children	BRC	Paediatric/Adult
Dublin, Our Lady's Children's Hospital	OLS	Paediatric/Adult
Glasgow, Royal Hospital for Sick Children	RHS	Paediatric/Adult
Leeds General Infirmary	LGI	Paediatric/Adult
Leicester, Glenfield Hospital	GRL	Paediatric/Adult
Liverpool, Alder Hey Hospital	ACH	Paediatric/Adult
London, Evelina London Children's Hospital	GUY	Paediatric/Adult
London, Great Ormond Street Hospital for Children	GOS	Paediatric/Adult
London, Harley Street Clinic	HSC	Paediatric/Adult
London, Royal Brompton Hospital	NHB	Paediatric/Adult
Newcastle, Freeman Hospital	FRE	Paediatric/Adult
Southampton, Wessex Cardiothoracic Centre	SGH	Paediatric/Adult
Blackpool Victoria Hospital	UHW	Adult
Basildon, Essex Cardiothoracic Centre	BAS	Adult
Birmingham, Queen Elizabeth Hospital	QEB	Adult
Brighton, Royal Sussex County Hospital	RSC	Adult
Cardiff, University Hospital of Wales	UHW	Adult
Glasgow, Golden Jubilee National Hospital	GJH	Adult
Liverpool Heart and Chest Hospital	BHL	Adult
London, Hammersmith Hospital	HAM	Adult
London, King's College Hospital	KCH	Adult
London, St George's Hospital	GEO	Adult
London, St Thomas' Hospital	STH	Adult
London, University College Hospital	UCL	Adult
Manchester Royal Infirmary	MRI	Adult
Manchester, BMI Alexandra Hospital	AHM	Adult
Nottingham City Hospital	CHN	Adult
Oxford, John Radcliffe Hospital	RAD	Adult
Sheffield, Northern General Hospital	NGS	Adult
Stoke, University Hospital of North Staffordshire	STO	Adult
Swansea, Morriston Hospital	MOR	Adult
Wolverhampton Heart & Lung Centre	NCR	Adult

## 5.2 Inclusion Criteria

Table two details the criteria for patient inclusion in the audit.

**Table 2**

<b>Analyses</b>	<b>Financial years</b>	<b>Age group</b>	<b>Inclusion criteria</b>
Aggregate: outcome at 30 days after paediatric cardiac surgery	2011/14	Under 16 years	All cardiac surgical procedures
Specific procedures: outcome at 30 days post procedure	2011/14	All age groups	All surgical and interventional procedures for congenital heart disease

A full list and definition of specific procedures can be found on the NCHDA website at <http://www.ucl.ac.uk/nicor/audits/congenital/datasets>. Please note that this report is based on Version 4.0 of the dataset.

## 5.3 Coding

The audit uses the European Paediatric Cardiac Code coding system ([www.aepc.org](http://www.aepc.org)), a subset of the International Paediatric and Congenital Cardiac Code (IPCCC, [www.ipccc.net](http://www.ipccc.net)). A full list of the codes is available via the NCHDA portal at <http://www.ucl.ac.uk/nicor/audits/congenital/datasets>.

## 5.4 Data Quality and Validation

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 but a relatively small number of adult congenital heart disease centres were visited in this way; those centres not visited were validated remotely using the methodology used by the National Adult Cardiac Surgery Audit at NICOR. 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) by comparing the data entered into the NICOR database with the actual patient records during a site validation visit. Typically, NICOR would expect the DQI to be greater than 90%.

## 5.5 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 2013/14. The analysis includes all patients under 12 months of age who undergo surgical and transcatheter procedures, excluding patent ductus, patent foramen ovale or atrial septal defect, as these conditions are not diagnosed antenatally.

## 5.6 Statistical Methodology

### *Small numbers*

Due to the relatively small number of cases, the report provides composite 3 year results for data submitted between April 1<sup>st</sup> 2011 and March 31<sup>st</sup> 2014.

## *Risk adjustment*

All centre aggregated analysis was conducted using PRAiS software (Partial Risk Adjustment in Surgery, 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. More information on the PRAiS model is available via the UCL Clinical Operational Research Unit: <http://www.ucl.ac.uk/operational-research/AnalysisTools/PRAiS> .

The PRAiS model has only been validated on paediatric cardiac surgery data so cannot be used to reliably predict adult congenital surgical 30 day outcomes or outcomes after interventional procedures.

## *Control limits*

The audit uses two control limits: 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 Unit has a 1 in 40 chance of reaching the 'warning' limit and 1 in 1000 chance of 'alert' limit.

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: control limits set at 97.5% (2 sd) and 99.9% (3 sd).

Note: as there are only 14 centres in the paediatric analysis this means that there is a 25.5% risk of at least one centre being beyond the 97.5% limit and a 1.35% chance of being beyond the 99.9% limit by random chance (i.e. a false outlier).

## **6. Findings**

### **6.1 Number of Specific Procedures**

Centres submitted data on 22,719 specific procedures between 2011 and 2014; 16,159 were paediatric cases and 6,546 were adult cases (in 14 cases age the date of birth was not submitted). A more detailed breakdown by centre and age group is available on the NCHDA portal.

Antenatal diagnosis analysis is based on 12,308 procedures undertaken between April 2010 and March 2014 on patients who then had a surgical or interventional procedure in their first year of life.

### **6.2 Data Quality Indicators**

Table 3 provides the data quality indicator (DQI) scores at each centre for both surgical and catheter procedures. Nearly all centres had DQI scores of 90% and above. 90% is considered the acceptable threshold for data quality. Above 95% is excellent (shown in bold in the table). 100% is optimal.

The exceptions were adult (ACHD) centres Nottingham, Kings and Stoke, with DQI scores of significantly less than 90%; these centres have received detailed feedback including recommendations on how to improve data quality.

Overall the average DQI has improved year on year for paediatric centres, and although more erratic for adult (ACHD) centres, 2013-14 has shown improvement.

**Table 3: % Completeness (DQI) of key variables - at casenote review**

Hospital	CCAD Code	2011-12			2012-13			2013-14		
		Overall DQI %	DQI for Surgery	DQI for Catheter	Overall DQI %	DQI for Surgery	DQI for Catheter	Overall DQI %	DQI for Surgery	DQI for Catheter
Belfast, Royal Victoria Hospital	<b>RVB</b>	<b>97</b>	<b>97.5</b>	<b>96.25</b>	<b>98.2</b>	<b>98.1</b>	<b>98.5</b>	<b>95.75</b>	<b>96.75</b>	<b>95.25</b>
Birmingham Children's Hospital	<b>BCH</b>	<b>95</b>	<b>95.75</b>	94.25	<b>98</b>	<b>98</b>	<b>98</b>	<b>96.5</b>	<b>96.75</b>	<b>97</b>
Bristol Royal Hospital For Children	<b>BRC</b>	<b>95</b>	91	<b>96.25</b>	91.75	87	<b>96.5</b>	<b>96.5</b>	<b>98.25</b>	93.25
Dublin, Our Lady's Children's Hospital	<b>OLS</b>	92.75	92.5	92.75	<b>95.5</b>	<b>97</b>	94	<b>96.5</b>	<b>96.25</b>	<b>96.5</b>
Glasgow, Royal Hospital for Sick Children	<b>RHS</b>	<b>95.75</b>	<b>96</b>	<b>97</b>	<b>98.5</b>	<b>99</b>	<b>99</b>	<b>98.5</b>	<b>97.5</b>	<b>99.5</b>
Leeds General Infirmary	<b>LGI</b>	93.5	92	<b>95.75</b>	94.75	94.25	<b>96</b>	<b>97.75</b>	<b>95.25</b>	<b>99</b>
Leicester, Glenfield Hospital	<b>GRL</b>	93.25	94.75	91.75	94	<b>95.75</b>	90	90.5	94	85.5
Liverpool, Alder Hey Hospital	<b>ACH</b>	<b>95</b>	94.25	<b>96.25</b>	<b>96</b>	<b>96</b>	92.75	94.75	<b>96</b>	92.25
London, Evelina London Children's Hospital	<b>GUY</b>	<b>97.5</b>	<b>97</b>	<b>98.75</b>	<b>97</b>	<b>97.5</b>	<b>96.5</b>	<b>97</b>	<b>98</b>	94.25
London, Great Ormond Street Hospital for Children	<b>GOS</b>	<b>98</b>	<b>98</b>	<b>97.5</b>	<b>99</b>	<b>98.25</b>	<b>98</b>	<b>99.5</b>	<b>99.5</b>	<b>99.5</b>
London, Harley Street Clinic	<b>HSC</b>	94.75	93.75	<b>98</b>	<b>95</b>	94.75	<b>96</b>	<b>95.75</b>	<b>96.5</b>	94.5
London, Royal Brompton Hospital	<b>NHB</b>	<b>99</b>	<b>99.75</b>	<b>98.25</b>	<b>97</b>	<b>97.86</b>	<b>96.43</b>	<b>98</b>	<b>99.25</b>	<b>96.25</b>
Newcastle, Freeman Hospital	<b>FRE</b>	<b>95.5</b>	93.25	<b>99</b>	<b>98</b>	<b>97</b>	<b>99</b>	<b>96.75</b>	<b>97.25</b>	<b>95.5</b>
Oxford, John Radcliffe Hospital	<b>RAD</b>	93.25	95.25	87.25	92.5	n/a	92.5	Remote validation		
Southampton, Wessex Cardiothoracic Centre	<b>SGH</b>	<b>99</b>	<b>98.75</b>	<b>99.75</b>	<b>96.5</b>	<b>98.75</b>	<b>99.75</b>	<b>98</b>	<b>98.25</b>	<b>98.25</b>
Basildon, Essex Cardiothoracic Centre	<b>BAS</b>	not visited - insufficient procedures			not visited - insufficient procedures			Remote validation		
Birmingham, Queen Elizabeth Hospital	<b>QEB</b>	92	N/A	92	90	89	90	77	82.25	79.75

Hospital	CCAD Code	2011-12			2012-13			2013-14		
		Overall DQI %	DQI for Surgery	DQI for Catheter	Overall DQI %	DQI for Surgery	DQI for Catheter	Overall DQI %	DQI for Surgery	DQI for Catheter
Blackpool, Victoria Hospital		not visited - insufficient procedures			not visited - insufficient procedures			Remote validation		
Cardiff, University Hospital of Wales	<b>UHW</b>	86.75	77	93.25	82.5	72.5	87.25	Remote validation		
Brighton, Royal Sussex County Hospital	<b>RSC</b>	89.5	N/A	89.5	90.5	n/a	n/a	Remote validation		
Glasgow, Golden Jubilee National Hospital	<b>GJH</b>	<b>95</b>	<b>96</b>	91.5	94	93	<b>97.75</b>	<b>97.5</b>	<b>98.5</b>	<b>95.25</b>
Liverpool Heart and Chest Hospital	<b>BHL</b>	91	N/A		<b>97.5</b>	n/a	<b>97.5</b>	Remote validation		
London, Hammersmith Hospital	<b>HAM</b>	93.75	N/A	93.75	90	n/a	90	Remote validation		
London, King's College Hospital	<b>KCH</b>	83.75	N/A	83.75	85%	n/a	85	Remote validation		
London, St George's Hospital	<b>GEO</b>	90.5	N/A	90.5	90.75	90	91	Remote validation		
London, St Thomas' Hospital	<b>STH</b>	<b>97.5</b>	<b>97</b>	<b>98.75</b>	<b>97.75</b>	n/a	<b>97.75</b>	Unified with Evelina London Children's Hospital		
London, University College Hospital	<b>UCL</b>	94.75	94.75	94.75	94.25	<b>96.5</b>	93.5	Remote validation		
Manchester Royal Infirmary	<b>MRI</b>	89.25	87.75	92.25	93.5	93.75	93	<b>95</b>	<b>97.75</b>	92.25
Manchester BMI Hospital	<b>AHM</b>	Not visited - insufficient procedures			Not visited - insufficient procedures			Remote validation		
Nottingham City Hospital	<b>CHN</b>	69.5	n/a	n/a	68.75	n/a	68.75	Remote validation		
Sheffield, Northern General Hospital	<b>NGS</b>	<b>96.25</b>	<b>98</b>	94	94	94.75	93.25	Remote validation		
Stoke, University Hospital of North Staffordshire	<b>STO</b>	83	N/A	83	2.5	n/a	n/a	Remote validation		
Swansea, Morriston Hospital	<b>MOR</b>	not visited - insufficient procedures			not visited - insufficient procedures			Remote validation		
Wolverhampton, New Cross Hospital	<b>NCR</b>	not visited - insufficient procedures			not visited - insufficient procedures			Remote validation		
<b>Average for paediatric units</b>		95.6	95.3	95.9	96.1	96.4	96.2	96.6	97.1	95.5
<b>Average for ACHD units</b>		90.3	92.2	92.5	85.6	91.8	91.6	92.6	93.9	91.8

### 6.3 Surgical and Interventional Procedures: 30 day survival rates by Specific Procedures

Thirty-day survival was analysed in 56 important surgical and transcatheter cardiovascular interventions undertaken to treat congenital heart disease at any age. In all hospitals 30 day survival was above the alert limit for all procedures. The 30 day survival was above the warning limit for all procedures for all hospitals, with the exception of one paediatric surgical procedures (Norwood Stage I) at the Evelina London Children's Hospital, which exceeded the warning limit but not the alert limit. A response from the hospital is available on the NCHDA portal. Following a review of the response from Evelina, the NCHDA Steering Committee concluded that there was no evidence to suggest that further action is required. The Steering Committee made a number of recommendations relating to ongoing surveillance of outcome data. These have been included in a formal response from NICOR and the professional societies, which is available on the NCHDA portal.

All 30-day survival for all other procedures in all hospitals for paediatric and adult (ACHD) cases were as predicted.

The results of all 56 procedures for children and adults are available on the NCHDA public portal: [https://nicor5.nicor.org.uk/CHD/an\\_paeds.nsf/vwContent/home?Opendocument](https://nicor5.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument)

### 6.4 Surgical Procedures: 30 day risk adjusted survival rates (Paediatrics)

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.

Table 4 and Figure 1 show the number of surgical episodes, 30 day survival rates and the actual versus predicted survival ratio for paediatric surgery only.

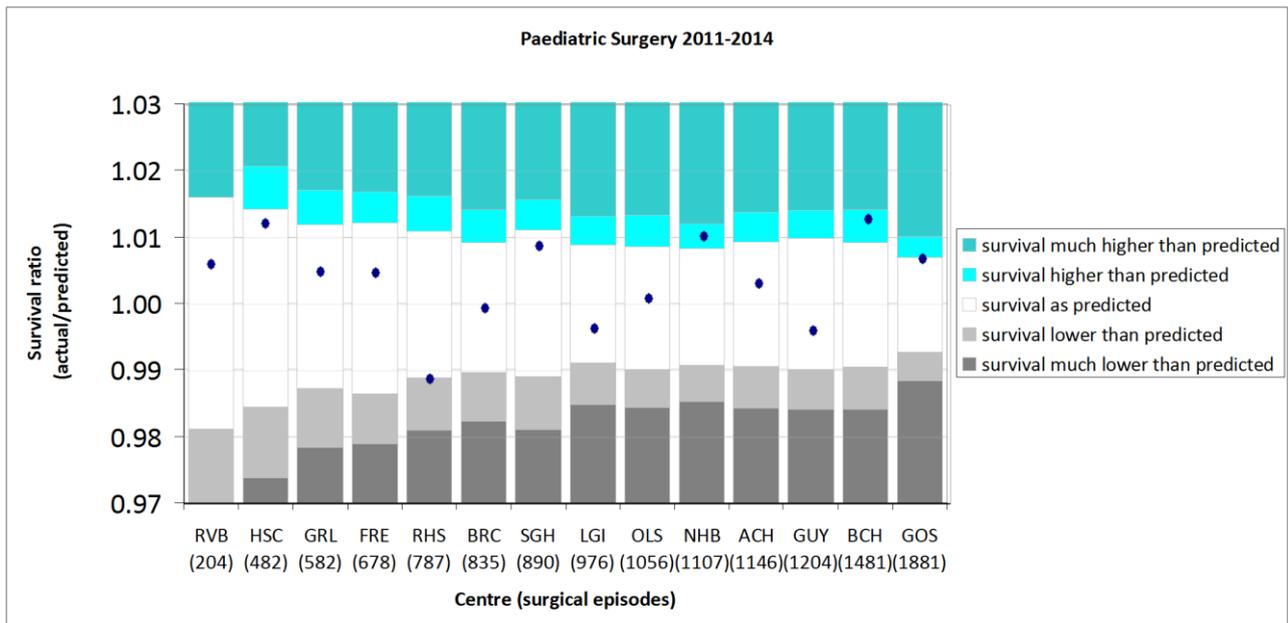
The results show that all hospitals were above both the alert limit of 99.5% and the warning limit of 97.5%, for 30 day predicted survival rates.

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.

**Table 4: 2011-2014 Paediatric surgical outcome analysis risk-adjusted using PRAiS model**

<b>Hospital</b>	<b>Code</b>	<b>Surgical Episodes</b>	<b>Actual Survival</b>	<b>Predicted Survival</b>	<b>Actual/Predicted</b>	<b>Survival summary</b>
Belfast, Royal Victoria Hospital	RVB	204	99.0%	98.4%	100.6%	as predicted
Birmingham Children's Hospital	BCH	1,481	98.0%	96.8%	101.3%	better than predicted
Bristol Royal Hospital For Children	BRC	835	97.7%	97.8%	99.9%	as predicted
Dublin, Our Lady's Children's Hospital	OLS	1,056	97.8%	97.8%	100.1%	as predicted
Glasgow, Royal Hospital for Sick Children	RHS	787	96.4%	97.5%	98.9%	as predicted
Leeds General Infirmary	LGI	976	97.6%	98.0%	99.6%	as predicted
Leicester, Glenfield Hospital	GRL	582	98.1%	97.6%	100.5%	as predicted
Liverpool, Alder Hey Hospital	ACH	1,146	97.6%	97.4%	100.3%	as predicted
London, Evelina London Children's Hospital	GUY	1,204	96.8%	97.2%	99.6%	as predicted
London, Great Ormond Street Hospital for Children	GOS	1,881	98.4%	97.7%	100.7%	as predicted
London, Harley Street Clinic	HSC	482	98.6%	97.4%	101.2%	as predicted
London, Royal Brompton Hospital	NHB	1,107	98.9%	97.9%	101.0%	better than predicted
Newcastle, Freeman Hospital	FRE	678	97.8%	97.3%	100.5%	as predicted
Southampton, Wessex Cardiothoracic Centre	SGH	890	98.1%	97.3%	100.9%	as predicted



**Figure 1: PRAiS-mediated outcome analysis: paediatric cardiac surgery 2011-2014**

Figure 1 shows on the Y-axis the survival ratio (actual survival/predicted survival) for all units, and the number of surgical 30-day episodes on the x-axis. The dot represents the actual performance on a unit. The shaded bars represent control limits as previously described. All units' performance falls in the white area, which indicates "survival as expected".

VLAD Chart from 01/04/2011 to 31/03/2014

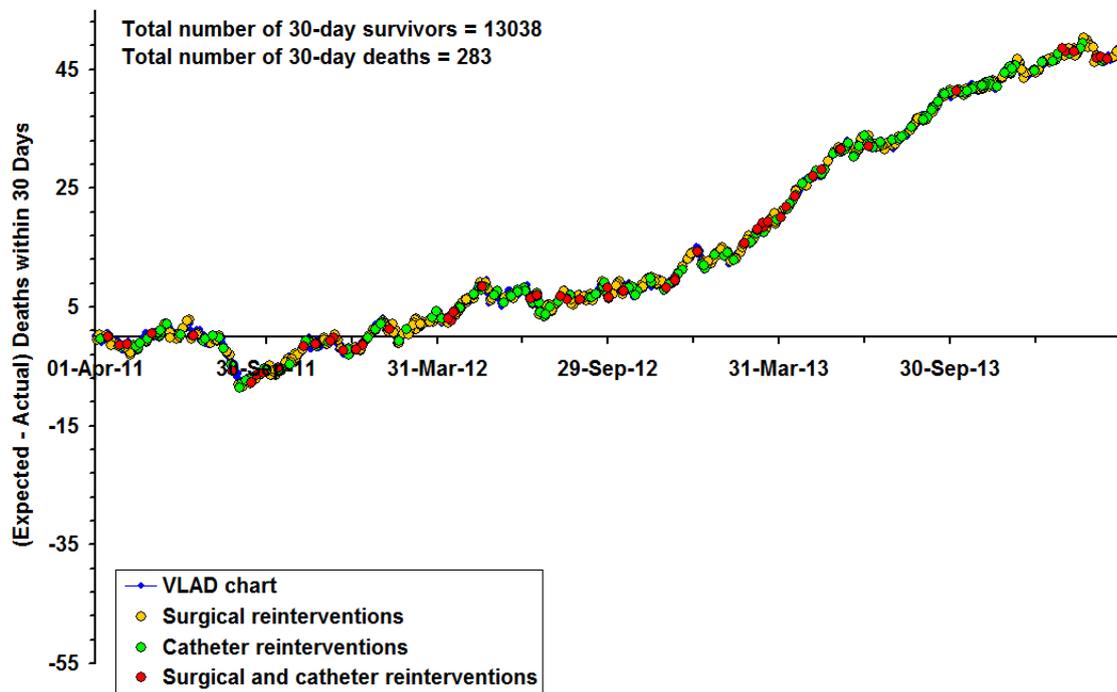


Figure 2: PRAIS-mediated outcome analysis: Variable Life Adjusted Display (VLAD) for paediatric cardiac surgery 2011-2014 for all centres in Great Britain and Ireland.

Y-axis shows (predicted-actual) deaths at 30 days. A positive value indicates improved survival. It can be seen that recent trends in outcomes have been positive, with survival improving in the most recent 18 months.

## 6.5 Antenatal detection and diagnosis of congenital heart disease

### *Detection rates*

Table 5 reflects the percentage rates of detection of congenital heart disease during the antenatal period across Great Britain and Ireland.

**Table 5: Rates of antenatal detection**

Country	2010-11	2011-12	2012-13	2013-14
England	38.1%	40.0%	42.5%	46.9%
Ireland	21.8%	37.0%	32.6%	38.1%
N Ireland	31.6%	36.0%	33.8%	38.6%
Scotland	29.7%	37.3%	46.6%	37.6%
Wales	47.3%	60.9%	56.1%	54.7%
GB and Ireland (overall)	36.1%	40.3%	42.2%	45.7%

### *Diagnosis rates*

Table 5 show the trend in the Great Britain and Ireland towards improved antenatal diagnosis over the past 4 (financial) years.

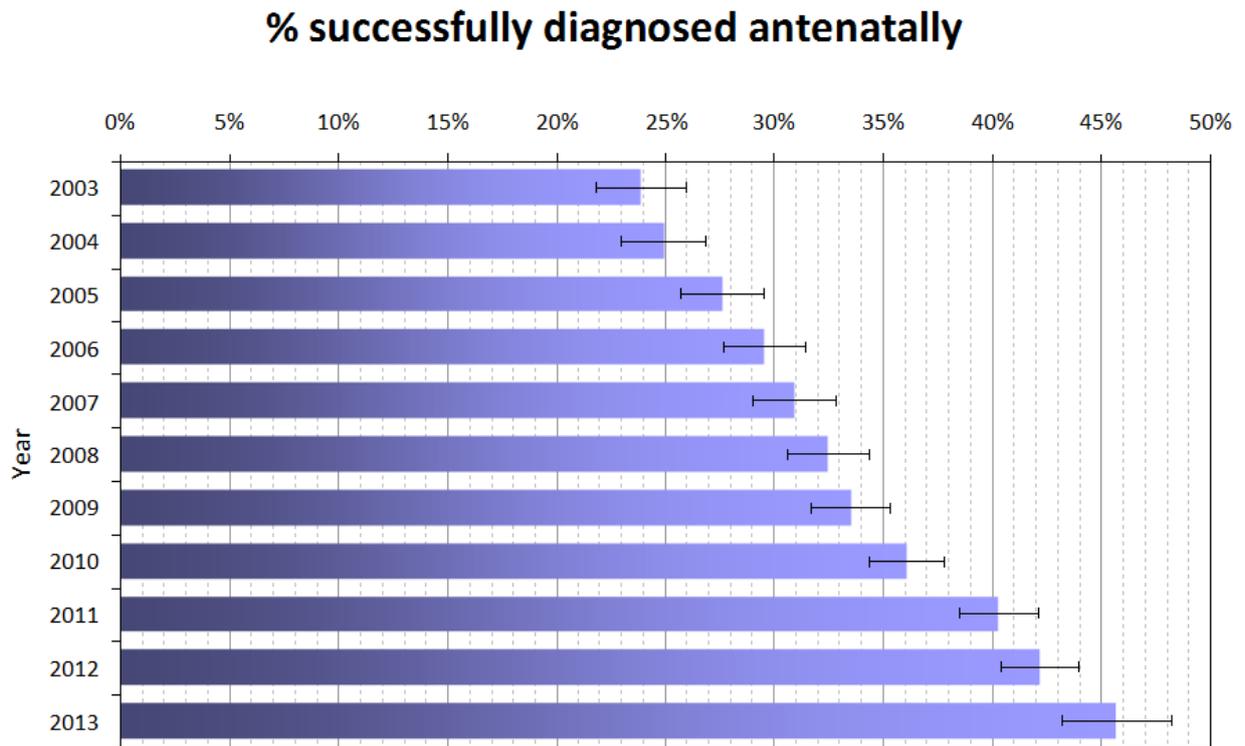
The value shown is the percentage of eligible cases that were successfully diagnosed antenatally. Please note this is not the same as the overall antenatal *detection* rate as it does not take into account deaths during pregnancy, termination of pregnancy, or perinatal deaths or deaths in infancy in infants with congenital heart malformations who did not have a procedure.

Figure 3 shows the overall average % successfully diagnosed antenatally from 1 April 2003-31 March 2014 (financial years). There is a steady improvement year on year, from below 25% in 2003-04 to nearly 45% in 2013-14.

Despite this, marked regional variations can be seen on the map in Figure 4, covering the last 5 financial years. The most recent financial year breakdown is available on the NCHDA website and includes tables of the percentage detection for each region illustrated for the financial years 2008-14 and 2013-14:

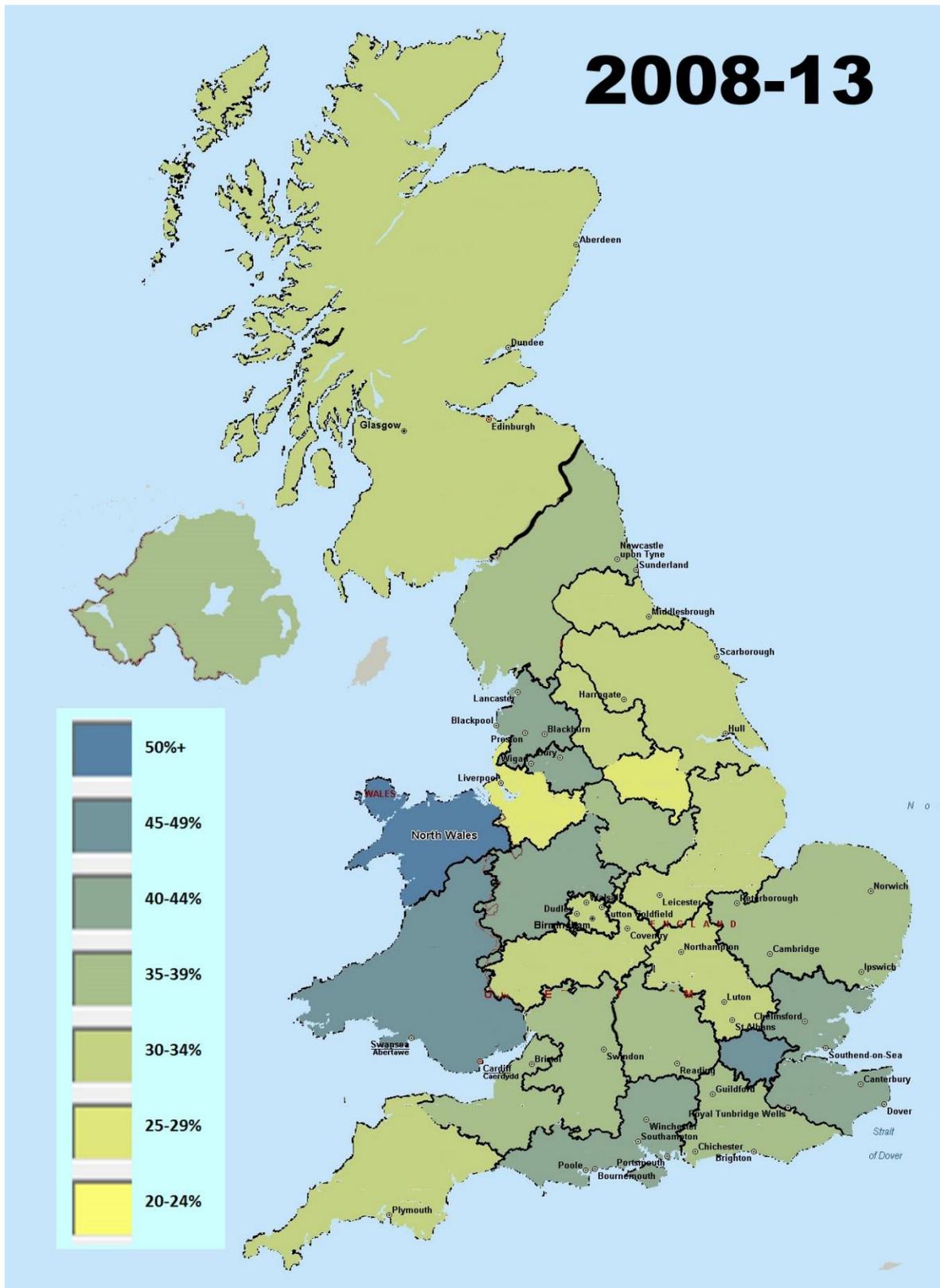
[https://nicor4.nicor.org.uk/CHD/an\\_paeds.nsf/vwContent/Antenatal%20Diagnosis?Opendocument](https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Antenatal%20Diagnosis?Opendocument)

Figure 3: Trend in successful antenatal diagnosis 1 April 2003-31 March 2014



Standard error bars are shown for each value.

Figure 4: Regional distribution of successful antenatal diagnosis 1 April 2008-31 March 2014



## 7. Conclusions

Data quality (completeness of valid data) continues to improve although some units require to address their deficits.

All hospitals had outcomes either 'as predicted' or 'better than predicted', as assessed using the PRAiS risk adjustment model, as assessed by using the PRAiS risk adjustment model.

One hospital reached the warning limit (98%; green line) for one procedure. NICOR has alerted the medical director and the relevant professional societies, in line with Department of Health guidance on managing outliers. 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, Evelina London Children's Hospital has provided a formal response that is available on the NCHDA portal.

Analysis of all hospitals showed an upward trend in survival in the most recent 18 months. The overall survival for all congenital heart disease procedures is extremely high and compares very well with data from international databases in Europe and North America. Please note that the NCHDA outcome measure presented is 30 day survival, which captures all deaths within 30 days of initial surgery even if death occurs outside the hospital, but does not capture deaths beyond 30 days.

For the 56 Specific Procedures used as a basis of inter-unit comparison, there were two alert-level outliers for paediatric cardiac surgery and none for paediatric intervention, adult (ACHD) cardiac surgery and adult (ACHD) intervention.

Antenatal diagnosis rates (analysed over the 5 year period 2008-2013) continue to rise but there is significant regional variation. Detection rates are now highest in North Wales.