



National Congenital Heart Disease Audit Report 2012-15



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.



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1. Executive Summary

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 currently detected by antenatal ultrasound scans. Congenital heart disease is relatively rare and requires specialist clinicians who have experience in treating paediatric and adult patients. Congenital heart disease services are a relatively small speciality accounting for just over 1% of NHS of specialised commissioning budget¹. Services are concentrated in a small number of centres to ensure there are a sufficient number of procedures to develop skills, experience, organisational processes and are on close proximity to other specialist services.

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 (RoI). The audit focuses on monitoring activity levels and outcomes following cardiovascular procedures and the success of cardiovascular antenatal diagnostic screening.

The audit aims to improve the quality of specialist congenital cardiovascular care by providing reliable data on activity levels, access to antenatal diagnosis and patient outcomes. Since 2007, the audit has published detailed results on the National Congenital Heart Disease Audit portal (<http://nicor4.nicor.org.uk>). The following report supplements the detailed results published on the portal and summarise the key findings.

National Congenital Heart Disease Audit data is used by a wide range of health organisations to support quality improvement:

- Specialist congenital heart disease centres use audit data to monitor the outcomes of patients following a procedure.
- Specialist commissioners monitor patterns of activity and the quality of care using metrics within the congenital cardiology Quality and Transitional Dashboards.
- The audit has supported the NHS England Congenital Heart Disease Service Review and provided information on activity, specialist advice on coding and reliability of HES data to across the NHS as a whole. NICOR has also undertaken an exploration of potential factors associated with suboptimal outcomes.
- The Care Quality Commission (CQC) and Healthcare Quality Improvement Partnership are developing information dashboards for use in CQC inspections. These are likely to be based on existing quality measures such as Data Quality Index and 30 day outcomes.
- Commissioning for Quality and Innovation (CQUIN) payment framework. The CQUIN payment framework enables commissioners to reward excellence, by linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals. Audit data is used to support this initiative.

1.1. Participation

The findings are based on data submitted by 14 combined 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 30,995 paediatric and congenital heart surgery and interventions undertaken between April 1st

¹ New Congenital Heart Disease Review: Final Report July 2015. <https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf>

2012 and March 31st 2015. The four age groups are:

- Neonate: Up to 30 days
- Infant: Between 31-365 days old
- Child: Between one and 16 years old
- Adult: 16 years and older

Data has undergone a rigorous validation process comprising site visits by a clinical data auditor and volunteer clinician to all paediatric sites and the higher volume adult sites, and has been verified by each local hospital as being accurate.

1.2. 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 thoracic cardiovascular malformation present from birth. This does not include surgery or therapeutic catheterisation for degenerative disease such as aortic aneurysm, dissection or coronary artery bypass surgery.

Due to the small number of cases involved there is a theoretical very small risk of identifying individuals. Therefore the report provides composite 3 year results for data submitted between April 1st 2012 and March 31st 2015. This is in line with the Office for National Statistics Confidentiality Guidance for publishing health statistics².

This risk adjustment method is a process used to account for the impact of individual risk factors such as the type of procedure itself with its inherent risks, age, coexistent conditions such as syndromes, severity of illness and other medical problems that can put some patients at greater risk of adverse outcomes than others. 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 73 surgical and transcatheter cardiovascular interventional procedures. The type of procedure undertaken at each hospital varies and full list of procedures including a glossary describing each procedure, is available on the NCHDA portal³.

The audit 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 in a paediatric patient, 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): an alert limit (98%) and an alarm limit (99.5%). If a unit's outcomes are above (i.e. 'better than') both limits then their performance is not statistically different from the national average.

Key Findings Patient

Outcomes

- Overall survival at 30-days following paediatric heart surgery was within the appropriate range for all specialist children's heart units (99.5% and 97.5% prediction limits).
- Overall survival at 30 days was analysed in 73 major surgical and transcatheter cardiovascular interventions undertaken to treat congenital heart disease at any age. In all hospitals 30 day survival was better than the alert limit (98%) for all procedures with two exceptions:

² Review of the Dissemination of Health Statistics: Confidentiality Guidance (2006). <http://www.ons.gov.uk/ons/guide-method/best-practice/disclosure-control-of-health-statistics/index.html>

³ https://nicor5.nicor.org.uk/CHD/an_paeds.nsf/WBenchmarksYears?openview&RestrictToCategory=2013&start=1&count=500

- Liverpool Heart and Chest Hospital was below the alert limit (98% confidence) for the atrial septal defect (ASD) surgical repair procedure (adult procedure).
- Evelina London Children's Hospital was below the alert limit (98% confidence) for the Norwood Procedure (Stage1) (paediatric procedure). Please note that although this is the second year in a row that Evelina has been found to be outlying for this procedure, this is due to an overhang effect as the outlier status was in fact restricted to 2013-14 30 day outcomes. All funnel plots are based on a three year rolling data given the relatively small number of procedures nationally and it was anticipated that this outlier status would persist until previously made changes have had the opportunity to work their way through and have had their anticipated positive clinical impact. In the 2014-2015 calendar year only three neonatal Norwood procedures were performed with 100% 30 day survival. Although positive this is an insufficient number to have had an impact on the figures over the 3 year period.

The NCHDA follows the Department of Health Outlier Policy⁴, which sets out a process for providing assurance that all hospitals provide the expected quality of care. This Policy is initiated when the results are outside the expected range. Centres who fall outside the expected range are sometimes referred to as 'outliers'. Both hospitals have been contacted by NICOR and the relevant professional societies. Hospitals are required to summarise information about the case, local clinical practice and if relevant, lessons learned. Responses from both hospitals have been reviewed by members of the NCHDA Steering Committee and the President/President-Elect of BCCA and SCTS and in both cases the quality of local services was assured with no ongoing concerns for patients and their families. Responses from both hospitals and the Professional Societies are provided on the portal/NICOR website <https://nicor5.nicor.org.uk/80257061003D4478.nsf/vwContent/home?OpenDocument>

Success of antenatal diagnosis

- Antenatal diagnosis of congenital heart disease has improved over the past 7 years. Between 2010-15, almost 50% (n = 14,251) of infants who required a procedure to treat a congenital heart malformation in first year of life were diagnosed through antenatal screening, compared to less than a quarter of cases in 2004/5. This is as good as, or better than, annual reported diagnostic rates in North America from 2006-12.

Activity

- Monitoring patterns of activity and outcomes by centre is a key to ensuring procedures are undertaken by centres that offer specialist expertise. In 2014-15, UK and RoI centres submitted data on 8,216 specific procedures; 5,887 were paediatric cases and 2,329 were adult cases. A more detailed breakdown by centre and age group is available on the NCHDA portal⁵
- The NCHDA does not currently publish data on the rarest procedures due to the very small numbers involved. The 2012-15 analysis of the more frequent specific procedures covers 86% of transcatheter and 81% of surgical procedures. However, the PRAiS analysis for patients under 16 years of age is a composite assessment of all procedures undertaken by the specialist paediatric centres.

1.3. Summary of recommendations

I. Chief Executives, Medical Directors and Clinical Leads at Provider Centres

We recommend that you:

- Ensure that your Specialist Surgical Centre has a minimum of 1 WTE dedicated paediatric cardiac surgery/cardiology Database Manager, with at least 1 WTE assistant, responsible for audit and database

⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213767/dh_123888.pdf

⁵ https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/WSummaryYears?openview&RestrictToCategory=2013&start=1&count=500

submissions in accordance with necessary timescales. This recommendation is in accordance with the congenital cardiology Standards published as part of the NHS England new CHD review (July 2015).

- Ensure there are sufficient resources allocated to, and sufficient processes put in place to fully support national clinical audit activity, including local IT support and software that fully accommodates the NCHDA dataset for timely submission of data and verification of data quality.
- Ensure all patients undergoing CHD procedures have a preceding congenital cardiology MDT, in accordance with the congenital cardiology Service Specification published as part of the NHS England new CHD Review (2015).
- Provide appropriate clinical support to the clinical audit teams. Our data show that higher level of clinical engagement with the clinical audit team is associated with a better data completeness and data quality. Each clinical audit should have an identified Clinical Audit Lead assigned to support this activity.
- Ensure all operators regularly review their data submitted to the NCHDA to improve timeliness and accuracy (monthly for large centres).
- Engage with the NCHDA annual validation site visit reports, considering and implementing recommendations therein.
- Ensure that all centres undertaking congenital cardiology procedures submit data to the NCHDA, including adult patients with CHD.

II. Congenital Cardiology Clinical Audit Teams

We recommend that you:

- Ensure there are Standard Operating Protocols in place that ensure timely and accurate NCHDA data submissions on at least a quarterly basis, as well as reverse validation of submitted data (monthly for large centres). More contemporaneous data submission is associated with better data completeness and data quality.
- Check that the data submitted to NICOR shows what you expect it to (reverse validation); this is especially relevant to those hospitals that use third party software to submit their data.
- Ensure there are regular meetings between the database manager(s) and Clinical Audit Leads (surgical and interventional catheter) to internally check data quality (monthly for large centres).
- Ensure that those centres undertaking paediatric congenital cardiology operations present and review their internal VLAD plots generated by the PRAiS analyses at monthly congenital cardiology MDT mortality & morbidity meetings, documenting discussions and resulting action points. This is one of the Quality Dashboard metrics submitted to Specialist Commissioners.
- Encourage senior congenital cardiology trainees (ST6-7) to be actively involved in the NCHDA process and volunteer to be an assisting clinician on at least one external validation visit prior to seeking a Consultant post.

III. Patients and Public

- This report, along with the NCHDA web Portal, allows you to review of activity of local centres as well outcomes such as survival following major procedures. It provides comparison of risk adjusted mortality between paediatric centres, identifies alerts and alarms and subsequent responses from specialist centres.

2. Introduction

2.1. Congenital Heart Disease

Congenital heart disease refers to any defect of the thoracic cardiovascular system that is present from birth. It includes structural defects, congenital arrhythmias, and a minority of cardiomyopathies. Acquired heart disease develops after birth and may occur in childhood; examples include inflammatory heart disease such as rheumatic heart disease and myocarditis, as well as most cardiomyopathies.

At least 8 in every 1,000 babies are born with a heart or circulatory condition and currently only a quarter of these are detected by antenatal ultrasound scans. The diagnosis and treatment of complex heart malformations has improved over the past few decades. As a result, almost all children born with complex heart defects survive to adulthood⁶. Congenital heart disease is relatively rare and related healthcare requires specialist clinicians who have specific training and experience in this field. In the UK and Republic of Ireland, the great majority of major procedures are undertaken at dedicated congenital heart disease centres.

Poor antenatal diagnosis rates suggest that there is reduced opportunity for comprehensive counselling during pregnancy for parents expecting a baby with significant congenital heart disease, as well as compromising the ability to deliver optimal care for such infants following delivery. Failure to recognize and promptly treat major congenital heart disease is associated with increased morbidity and mortality rates, and is recognized as an important quality-of-care issue.⁷

2.2. The role of the National CHD Audit

The Audit aims to improve the quality of care for children and adults with congenital heart disease by providing national comparative analysis of activity and outcomes following cardiac surgery and therapeutic cardiac catheterization procedures. The audit currently provides the following information:

- Overall survival at 30-days after paediatric heart surgery for all paediatric specialist centres, as an aggregate of all procedures undertaken (PRAiS analysis).
- Overall survival at 30-days for each of the 73 surgical and transcatheter cardiovascular interventions both in children and adults.
- Rates of overall antenatal diagnosis of congenital heart disease by region and country.

The audit collects data from all centres undertaking major congenital heart disease procedures in England, Scotland, Wales, Northern Ireland and the Republic of Ireland. Information is broken down into four age groups:

- Neonate: Up to 30 days
- Infant: Between 31-365 days old
- Child: Between one and 16 years old
- Adult: 16 years and older

2.3 Supporting Quality Improvement

The NCHDA has been publically reporting outcomes for surgical and interventional procedures for over a decade

⁶ Brown KL, Crowe S, Franklin R, McLean A, Cunningham D, Barron D, Tsang V, Pagel C, Utley M. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. *Open Heart* 2015;2:e000157. doi:10.1136/openhrt-2014-000157

⁷ Prenatal screening for major congenital heart disease: assessing performance by combining national cardiac audit with maternity data. Gardiner HM1, Kovacevic A, van der Heijden LB, Pfeiffer PW, Franklin RC, Gibbs JL, Averiss IE, Larovere JM. *Heart*. 2014 Mar;100(5):375-82. doi: 10.1136/heartjnl-2013-304640. Epub 2013 Nov 22

and aims to improve the quality of specialist services by:

- Monitoring activity and outcomes by collecting reliable like-with-like data on all congenital cardiovascular disease procedures, enabling centres to target improvement initiatives to specific procedures, if performance is found to be below that predicted. This involves verifying life status at 30 days, and 1 year after the procedure date with ONS to provide reliable information about the immediate and short term outcomes for children. Please note, life status at one year is only published on the public portal due to the time difference in reporting. One year life status for patients admitted between April 1st 2014 and March 31st 2015 will be published in August 2016, as we need to wait 12 months after March 31st 2015, as well as having confirmation of life status from ONS.
- Sharing data for use in a wide range of quality improvement initiatives and acting on the findings. Examples of how data is used to improve quality include local audit, NHS England service review of congenital heart disease services, development of national quality indicators and outcomes based research (Table 1).
- Reporting on the success of antenatal diagnosis of severe congenital heart disease (requiring a procedure in infancy) at a regional level, in order to target quality improvement efforts, such as through training and optimising sonographic equipment.

All of the specialist congenital heart disease centres submit data to the audit. However, although this is a mandatory audit, there are instances where some hospitals who undertake procedures for adults with congenital heart disease, do not submit data.

Table 1: Extended use of audit data

Quality improvement activity	Description
Local audit and Quality Dashboards for Specialist Commissioning	All specialist paediatric centres use internal PRAiS software to monitor and track near real time outcomes on a month by month basis using Variable Life Adjusted Display (VLAD) charts with respect to 30 day mortality in those under 16 years of age after surgical procedures, as well as related reinterventions rates. Centres are required to review their VLAD reports and report monthly to the Specialist Commissioners as part of the Transition and Quality Dashboards. Evidence of below predicted survival, and indeed all deaths, are discussed at regular multidisciplinary mortality and morbidity meetings, with resultant learning and quality improvement action points taken forward at a local level. The Quality Dashboard also requires centres to report on most recent 3 year mortality scores using their in house PRAiS data.
NHS England Service Review ¹	The NCHDA has supported the NHS England Service Review by providing the following analyses: <ul style="list-style-type: none"> • Advice was sought and given by the NCHDA Clinical Lead on coding structures (ICD-10 and OPCS) to be used when interrogating Hospital Episode Statistics (HES) in order to better understand any congenital heart procedures undertaken by the relatively few centres who do not submit their data to the NCHDA, particularly with respect to adult CHD activity. • Activity by age and centre • Exploratory analysis of factors that may impact on outcomes. Initial results of this work indicate that Asian ethnicity has a statistically significant association with outcome. Additional linked research has recently been submitted for peer review publication.
CQC data flows	From 2016, NCHDA audit data will be used to provide information for Care Quality Commission inspections.
Outcomes based research	NCHDA data is actively used for clinical research aimed at reporting outcomes locally and nationally. A full list of research projects is available on the NICOR website. An example of projects is provided in Appendix 2.

2.4 Organisation and governance of the audit

The audit 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). HQIP commissions work for the National Congenital Heart Disease Audit on behalf of NHS England, which funds the audit for England and Wales only. The NCHDA is funded by NHS England. Data included from other devolved nations or organisations outside of England and Wales are provided through separate arrangements between NICOR and those organisations. NICOR's mission is to provide accurate data on cardiovascular outcomes for the public, healthcare providers and the medical profession.

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.

3. Methodology

3.1. Participation

Analyses are based on 31,010 congenital heart disease surgical and interventional procedures undertaken between April 1st 2012 and 31st March 2015. Congenital heart disease procedures are defined as those performed for a cardiovascular defect or malformation present from birth. This report does not include surgery or therapeutic catheterisation for acquired or degenerative disease such as aortic aneurysm or dissection or coronary artery bypass surgery.

The NCHDA annual audit period is from April 1st to March 31st and the deadline for submitting 2014/15 data was May 4th 2015. Centres are listed in Table 2.

Table 2: Centres undertaking major congenital cardiac procedures 2012 - 2015		
Hospital undertaking Paediatric and ACHD procedures	Code	Number of procedures: Total (Paediatric/Adult cases)
Liverpool, Alder Hey Hospital	ACH	1893 (1838/55)
Birmingham Children's Hospital	BCH	2805 (2686/119)
Bristol Royal Hospital For Children	BRC	2273 (1515/758)
Newcastle, Freeman Hospital	FRE	1507 (1106/401)
London, Great Ormond Street Hospital for Children	GOS	3109 (2995/114)
Leicester, Glenfield Hospital	GRL	1534 (1101/433)
London, Evelina London Children's & St Thomas Hospitals	GUY	2578 (1956/622)
London, Harley Street Clinic	HSC	695 (591/104)
Leeds General Infirmary	LGI	2421 (1690/731)
London, Royal Brompton Hospital	NHB	2782 (1941/841)
Dublin, Our Lady's Children's Hospital	OLS	1891 (1857/34)
Oxford, John Radcliffe Hospital	RAD	321 (20/301)
Glasgow, Royal Hospital for Sick Children	RHS	1346 (1315/31)
Belfast, Royal Victoria Hospital	RVB	583 (302/281)
Southampton General Hospital	SGH	1911 (1423/488)
Hospital undertaking only Adult CHD procedures	Code	Number of procedures: Total (paediatric/ACHD)
BMI The Alexandra Hospital	AHM	3 (0/3)
Basildon, Essex Cardiothoracic Centre	BAS	9 (0/9)
Liverpool Heart and Chest Hospital	BHL	428 (1/427)
Nottingham City Hospital	CHN	87 (0/87)
London, St George's Hospital	GEO	103 (0/103)

Bristol, Glen Hospital	GHB	1 (0/1)
Glasgow, Golden Jubilee National Hospital	GJH	462 (0/462)
London, Hammersmith Hospital	HAM	111 (0/111)
London, King's College Hospital	KCH	68 (0/68)
Swansea, Morriston Hospital	MOR	2 (0/2)
Manchester Royal Infirmary	MRI	542 (0/542)
Wolverhampton Heart & Lung Centre	NCR	25 (0/25)
Sheffield, Northern General Hospital	NGS	69 (0/69)
Birmingham, Queen Elizabeth Hospital	QEB	423 (1/422)
Brighton, Royal Sussex County Hospital	RSC	172 (0/172)
Stoke, University Hospital of North Staffordshire	STO	126 (0/126)
London, University College Hospital	UCL	603 (0/603)
Cardiff, University Hospital of Wales	UHW	78 (0/78)
Blackpool Victoria Hospital	VIC	29 (0/29)
Coventry, University Hospital	WAL	5 (0/5)

3.2. Inclusion criteria

Table 3 details the criteria for patient inclusion in the audit.

Table 3: inclusion criteria for each analysis			
Analyses	Years	Age group	Inclusion criteria
Risk adjusted: outcome at 30 days after procedure.	2012/15	Under 16 years	All surgical procedures (risk adjusted)
Specific procedures: outcome at 30 days after procedure	2012/15	1. Under 16 years 2. 16 years and over	All surgical and interventional procedures for congenital heart disease

A full list and definition of specific surgical and transcatheter/electrophysiological interventional procedures can be found on the NCHDA website at <http://www.ucl.ac.uk/nicor/audits/congenital/datasets>, and in Appendix 1. The web site also provides information on the procedures undertaken at each of the centres.

3.3. Coding

The audit uses the European Paediatric Cardiac Code coding system (<http://www.aepc.org/european-paediatric-cardiac-codi/>), a subset of the International Paediatric and Congenital Cardiac Code (IPCCC 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>.

3.4. Data Quality and Validation

The audit uses a rigorous validation process comprising site visits by a clinical data auditor and volunteer clinician to ensure full case ascertainment and to validate the accuracy of the data submitted to the audit. The submitted data are also signed off and verified by each local hospital as being accurate by backwards checking with the NCHDA database of submitted data. In brief, all centres who submit ten or more cases (therapeutic surgery and/or catheter procedures) to the NCHDA qualify for a validation visit. The hospital records of 20 congenital patients are randomly selected to be reviewed. The data that the centre previously submitted to NICOR for these 20 patients is then checked against their hospital notes. As part of the feedback to the Centre, the Centre receives a quality score (the Data Quality Indicator (DQI)) on the case note validation. The 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 compared to actual patient records during a site validation visit. Typically, NICOR would expect the DQI to be great than 90%. In addition, theatre and catheter laboratory logbooks are meticulously examined to ensure all appropriate cases have been submitted, with correct procedure and diagnosis coding, adding and deleting cases as appropriate. Finally the records of all deceased cases in the audit year are examined to ensure the accuracy of diagnoses, procedure(s) undertaken and any additional comorbid factors, again comparing against the data submitted.

The above described process is seen as the 'gold standard' method for validation. The challenge has been to maintain this model while reducing the delay in the publication of data. In the last 3 years, the clinical data auditor and specialist centres have worked hard to reduce the validation timeframe to 7 months. This was achieved by moving to two different models. All specialist centres continue to have on site validation visits so that all but a relatively small number of adult congenital heart disease centres were visited in this way. The remaining centres were validated remotely and centres were asked to confirm the accuracy of activity reports.

In 2015, the NCHDA Steering Committee reviewed the feasibility of extending remote validation to all centres. Whilst supportive in principal, the group agreed to continue with the current model until centres have time to fully implement the new dataset and there is evidence to confirm that all centres are entering high quality data consistently with evidence of full case ascertainment. In 2016 the Audit will pilot additional remote methodologies to reduce the gap between the data collection period and publication

3.5. Antenatal Diagnosis

Since 2003, the NCHDA has been collecting data on whether the heart abnormality for which a procedure was undertaken was detected antenatally. The antenatal results are based on data submitted between 2003/4 to 2014/15. Analysis is restricted to include all patients under 12 months of age who undergo surgical and transcatheter procedures. The analysis excludes closure procedures for patent ductus, patent foramen ovale or atrial septal defect, as these conditions are not diagnosed antenatally.

3.6. Statistical methodology

3.2.1 Small numbers

Due to the small number of cases involved there is a very small risk of identifying individuals. Therefore the report provides composite 3 year results for data submitted between April 1st 2012 and March 31st 2015. This in line with the Office for National Statistics Confidentiality Guidance for publishing health statistics⁷.

3.2.2 Risk adjustment for paediatric surgery

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. The PRAiS software generates estimates of risk for all 30 day episodes of care and produces a Variable Life Adjusted Display (VLAD) chart covering the period of the data. VLAD charts allow hospitals to quickly identify trends in outcomes (positive or negative) for in-house discussion at monthly MDT meetings and that might warrant further investigation. More information on how to interpret a VLAD chart is provided alongside Figure 2 (page 20). 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.

3.2.1 Control limits

The audit uses two control limits: an alert limit (98%) and an alarm limit (99.5%) as per the Department of Health Guidance on detecting outliers. If a unit is above both limits then their performance is not statistically different from the national average.

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 s.d.) and 99.9% (3 s.d.).

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

⁷ Review of the Dissemination of Health Statistics: Confidentiality Guidance (2006). <http://www.ons.gov.uk/ons/guide-method/best-practice/disclosure-control-of-health-statistics/index.html>

99.9% limit by random chance (i.e. a false positive or negative outlier).

4. Findings

4.1. Number of procedures

In 2014-15, centres submitted data on 10,078 procedures, 7,258 were paediatric cases and 2,820 were adult cases (Table 4). The full analysis is based on data submitted between 1/4/2012 and 31/3/2015 (Table 5). Note that for simplicity Hybrid procedures are included in the Surgical procedure count in this table.

There has been a year on year increase in the number of procedures undertaken and activity levels have increased by almost 40% since 2000 and now appear to have largely stabilised over the last few years at over 10,000 cases per year (Table 6).

Antenatal diagnosis analysis is based on 14,251 procedures undertaken between April 2010 and March 2015 on patients who then had a surgical or interventional procedure in their first year of life.

Table 4: Number and type of cases submitted by UK and Republic of Ireland (RoI) centres in 2014-15

Type	Provider	Paediatric	Adult	Total
Interventional	England	2,265	1,577	3,842
Interventional	N Ireland	72	67	139
Interventional	Private	25	8	33
Interventional	RoI	252	12	264
Interventional	Scotland	147	44	191
Interventional	Wales	0	18	18
Surgical	England	3,787	943	4,730
Surgical	N Ireland	26	28	54
Surgical	Private	93	21	114
Surgical	RoI	338	3	341
Surgical	Scotland	253	93	346
Surgical	Wales	0	6	6

Table 5: Number and type of cases submitted by UK and Republic of Ireland (RoI) centres 2012-15

Type	Provider	Paediatric	Adult	Total
Interventional	England	6,713	4,749	11,478
Interventional	N Ireland	160	189	349
Interventional	Private	149	48	197
Interventional	RoI	801	29	830
Interventional	Scotland	505	128	633
Interventional	Wales	0	52	52
Surgical	England	11,560	2,896	14,456
Surgical	N Ireland	142	92	234
Surgical	Private	442	60	502
Surgical	RoI	1,056	5	1,061

Surgical	Scotland	810	365	1,175
Surgical	Wales	0	28	28

Table 6: Total number of cases submitted to the audit by financial year

FY	Surgery	Interventional	Hybrid	Total
2003-04	4,497	2,928	0	7,425
2004-05	4,346	3,032	0	7,378
2005-06	4,638	3,490	3	8,131
2006-07	4,794	3,769	7	8,570
2007-08	4,771	3,616	10	8,397
2008-09	4,949	3,910	14	8,873
2009-10	5,262	3,963	6	9,231
2010-11	5,852	4,310	6	10,168
2011-12	5,710	4,498	29	10,237
2012-13	5,849	4,372	16	10,270
2013-14	5,937	4,669	44	10,647
2014-15	5,543	4,517	62	10,078

4.2. Data Quality Indicators

Nearly all centres had DQI scores of 90% and above (Appendix 3). 90% is considered the acceptable threshold for data quality. Above 95% is excellent (shown in bold in the table). Overall the average DQI has improved year on year for paediatric centres, and although more erratic for adult (ACHD) centres, 2015-16 site visits looking at 2014-15 data have shown further improvement. All but one centre receiving an on-site validation visit in 2015-16 had an overall DQI score of over 90%. The exception was Queen Elizabeth Hospital, Birmingham with overall DQI score of 79%. Those centres not achieving the requisite standard of over 90% have consistently received detailed feedback including recommendations on how to improve data quality. These reports are available on the NCHDA web site.⁸

4.3. Surgical and Interventional Procedures: 30 day survival rates by Specific Procedures

Thirty-day survival was analysed in 73 major surgical and transcatheter/electrophysiological cardiovascular interventions undertaken to treat congenital heart disease at any age. This is a considerable increase from the previous 57 procedures reported. No hospital breached the alarm limit for any procedure. 30 day survival was also above the alert limit for all hospitals and all procedures, with two exceptions:

- Liverpool Heart and Chest Hospital was below the warning limit (98% confidence) for the Atrial septal defect (ASD) Repair procedure (adult procedure).
- Evelina London Children's Hospital was below the warning limit (98% confidence) for the Norwood Procedure (Stage1) (paediatric procedure).

In line with Department of Health Outlier Policy, both hospitals have been contacted by NICOR and the relevant professional societies. Hospitals are required to summarise information about the case, local clinical practice and if relevant, lessons learned. Responses from both hospitals have been reviewed by members of the NCHDA Steering Committee and the President/President-Elect of BCCA and SCTS and in both cases the quality of local services was assured. Responses from both hospitals and the Professional Societies are provided on the portal/NICOR website: [Responses to Outlier Identification](#)

The results for all 73 procedures for children and adults are available on the NCHDA public portal: [Specific Procedures 2012-15](#)

⁸ https://nicor4.nicor.org.uk/chd/an_paeds.nsf/vwContent/Data%20Quality%20Reports?Opendocument

A table of all procedures undertaken for congenital heart disease from April 2012 to March 2015 inclusive is available in Appendix 1. There are 73 distinct procedures reported, covering 85% of all procedures, along with a summation of the 15% of miscellaneous procedures reported with low individual procedure frequency. Please note that this is a listing of procedures undertaken at different ages. It does not equate to the number of patients, as a proportion of patients will have had more than one procedure during this three year period.

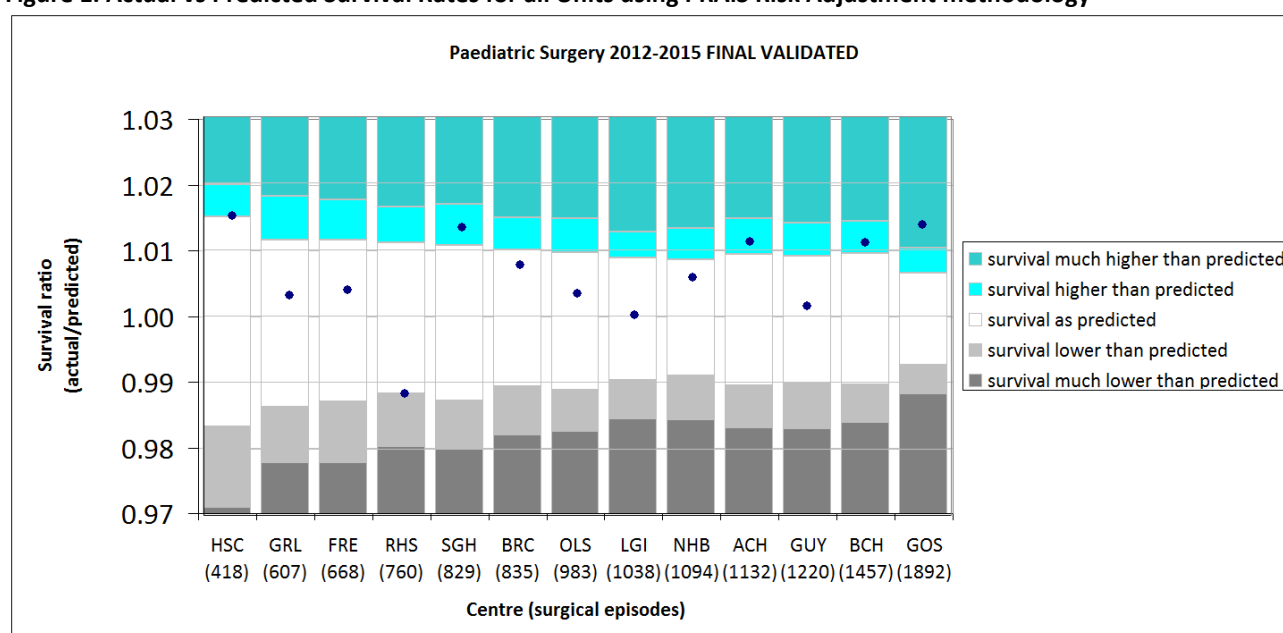
4.4. Surgical Procedures: 30 day risk adjusted survival rates (centre level aggregated data) -Paediatric cases only

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 8 and Figure 1 show the number of surgical episodes, 30 day survival rates and the actual versus predicted survival ratio for paediatric surgery only using PRAiS methodology.

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. It is also noteworthy and reassuring to families that 5 centres have results with an overall risk adjusted survival at 30 days higher than predicted level, one of whom (Great Ormond Street Hospital for Children) at a much higher than predicted level. There were two centres so performing in the 2011-14 analysis, one of whom (Birmingham Children's Hospital) has performed at this level for both analysis periods.

Please note that similar overall aggregate risk adjusted comparative figures for adults with congenital heart disease are not possible as no equivalent risk adjustment model currently exists for these patients.

Figure 1. Actual vs Predicted Survival Rates for all Units using PRAiS Risk Adjustment methodology



Note. Adjusted for procedure, age, weight, diagnosis, comorbidities and procedures performed.

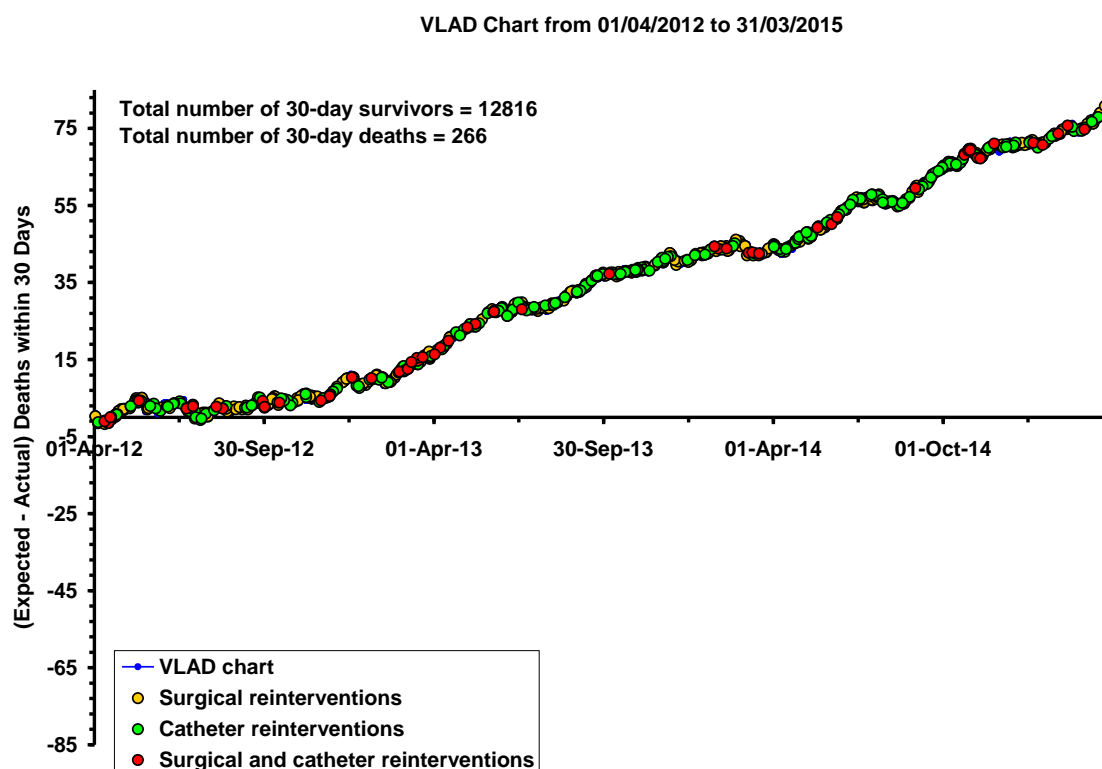
Figure 1 shows on the Y-axis the survival ratio (actual survival/predicted survival) for all units, and the number of surgical 30-day episodes on the x-axis. The dot represents the actual performance on a unit. The shaded bars represent control limits as previously described. The performance of all units falls in or above the white area, indicating survival as, or above, that predicted by the PRAiS risk adjustment model.

Table 8. Actual and Predicted Survival Rates 2012-15, using PRAiS Risk Adjustment methodology, for all units undertaking procedures in patients under 16 years of age

Hospital	Code	Surgical Episodes	Actual Survival	Predicted Survival	Actual/predicted	Survival Summary
London, Harley Street Clinic	HSC	418	98.8%	97.3%	1.015	as expected
Leicester, Glenfield Hospital	GRL	607	97.7%	97.4%	1.003	as expected
Newcastle, Freeman Hospital	FRE	668	97.8%	97.4%	1.004	as expected
Glasgow, Royal Hospital for Sick Children	RHS	760	96.3%	97.5%	0.988	as expected
Southampton, Wessex Cardiothoracic Centre	SGH	829	98.3%	97.0%	1.013	higher than expected
Bristol Royal Hospital For Children	BRC	835	98.3%	97.6%	1.008	as expected
Dublin, Our Lady's Children's Hospital	OLS	983	97.7%	97.3%	1.003	as expected
Leeds General Infirmary	LGI	1038	97.9%	97.9%	1.000	as expected
London, Royal Brompton Hospital	NHB	1094	98.3%	97.7%	1.006	as expected
Liverpool, Alder Hey Hospital	ACH	1132	98.2%	97.1%	1.011	higher than expected
London, Evelina Children's Hospital	GUY	1220	97.1%	97.0%	1.002	as expected
Birmingham Children's Hospital	BCH	1457	97.5%	96.5%	1.011	higher than expected
London, Great Ormond Street Hospital for Children	GOS	1892	99.0%	97.7%	1.014	much higher than expected

Figure 2. Variable Life Adjusted Display (VLAD) Chart for all 14 centres undertaking procedures in patients under 16 years of age, 2012-15.

Y-axis shows predicted minus actual deaths at 30 days. A positive value therefore indicates improved survival. Trends in outcomes continue to improve in 2014-15, with survival increasing markedly over the most recent 24 month period. In the 3 year period more than 75 fewer deaths were observed than were predicted, demonstrating the continuing rise in quality of congenital cardiac surgery in the UK and Ireland.



Interpreting the VLAD chart

Each point on the VLAD chart represents an episode of care (the first surgical procedure for a child in a 30-day care period). If the 30-day outcome is a survival then the VLAD plot goes up and if it is a death the VLAD plot goes down. The vertical axis is the total number of (predicted – actual) deaths. When this is positive there have been fewer than predicted deaths; when this is negative there have been more than predicted deaths.

A run of survivors will cause the VLAD plot to go up and a run of deaths will cause it to go down. Over time, if outcomes are as expected by the risk model, the end of the VLAD plot will tend to be close to zero. Ending close to zero is not a sign that things are not going well.

The risk model essentially benchmarks the unit's outcomes against recent national outcomes in paediatric heart surgery. Despite this being one of the most complex areas of surgery and lifesaving for the children involved, the UK has excellent outcomes with very low mortality rates. So the estimated risk of death for a patient is small and this means that the VLAD will rise much more slowly for a run of survivors than it will fall for a run of deaths.

Explanation kindly provided by Dr Christina Pagel (CORU) and Dr Kate Brown (GOSH)

4.5. Antenatal detection and diagnosis of congenital heart disease

Detection rates

Overall antenatal detection rates continue to improve (Figure 3) although there are differences between countries (Table 9) and regions within the UK (Figure 4a and 4b). Antenatal diagnosis rates are higher in the UK than in the US between 2006 and 2012, although the gap has narrowed in recent years (Figure 5).

The value shown is the percentage of eligible cases that were successfully diagnosed antenatally, i.e. those cases who required a surgical or interventional procedure during infancy. 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 overall average % successfully diagnosed antenatally from 2003 to 2015 (financial years).

Antenatal diagnosis rates (analysed over the 5 year period 2010-2015) continue to rise and regional variation has reduced. Detection rates are currently highest in Northern Ireland and several English regions (Appendix 4).

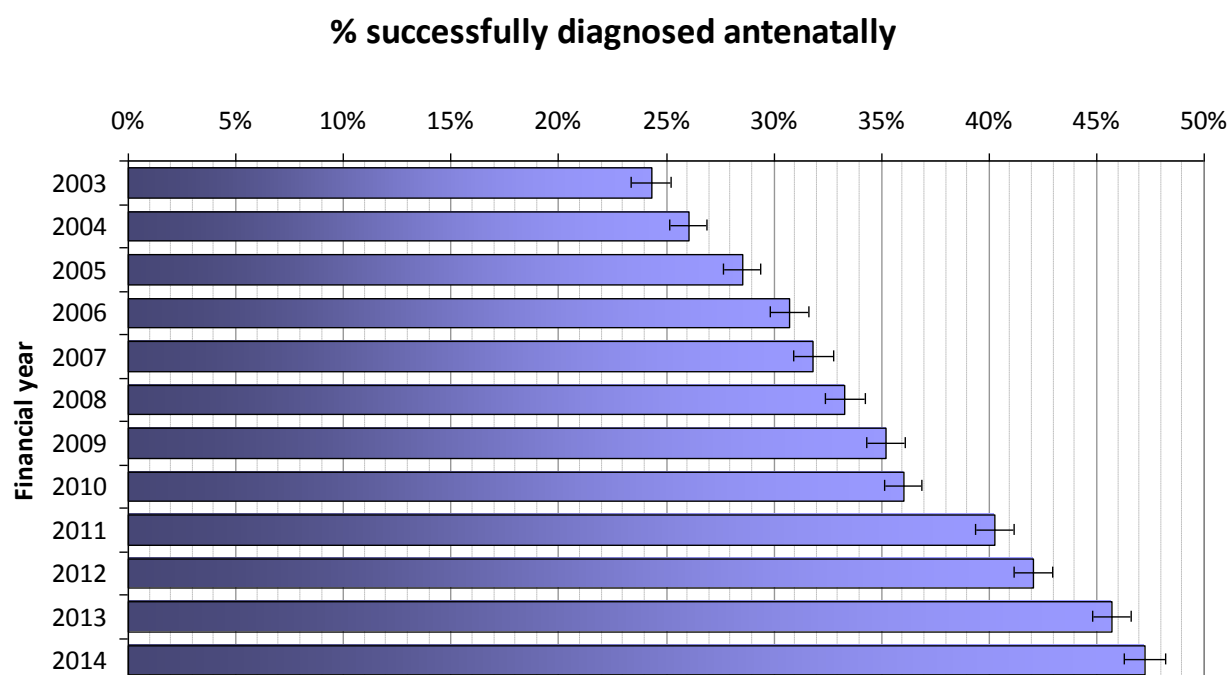


Figure 4: Regional distribution of successful antenatal diagnosis across UK and Republic of Ireland 2010-2015

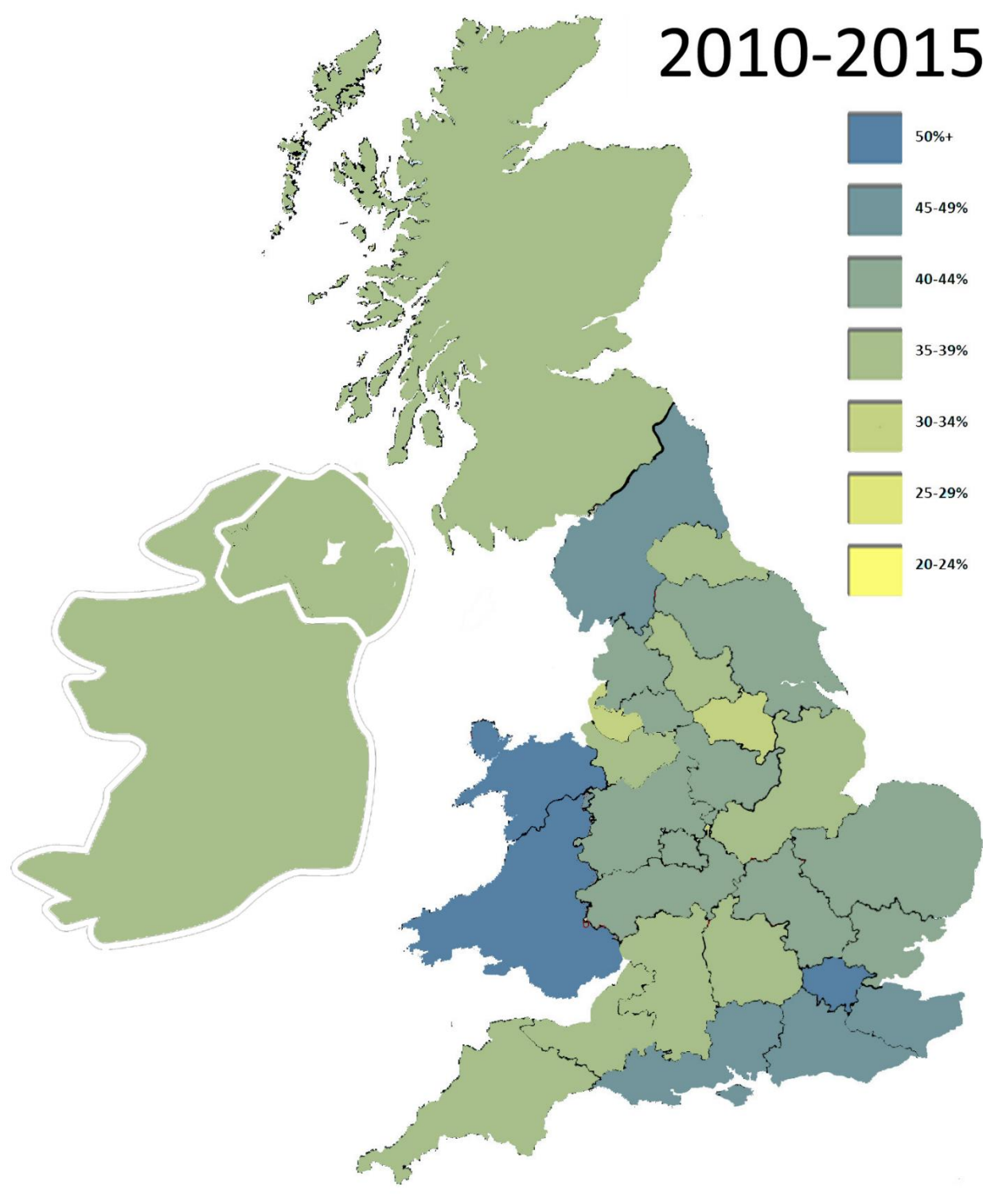


Figure 4b: Regional distribution of successful antenatal diagnosis across UK and Republic of Ireland 2014-2015

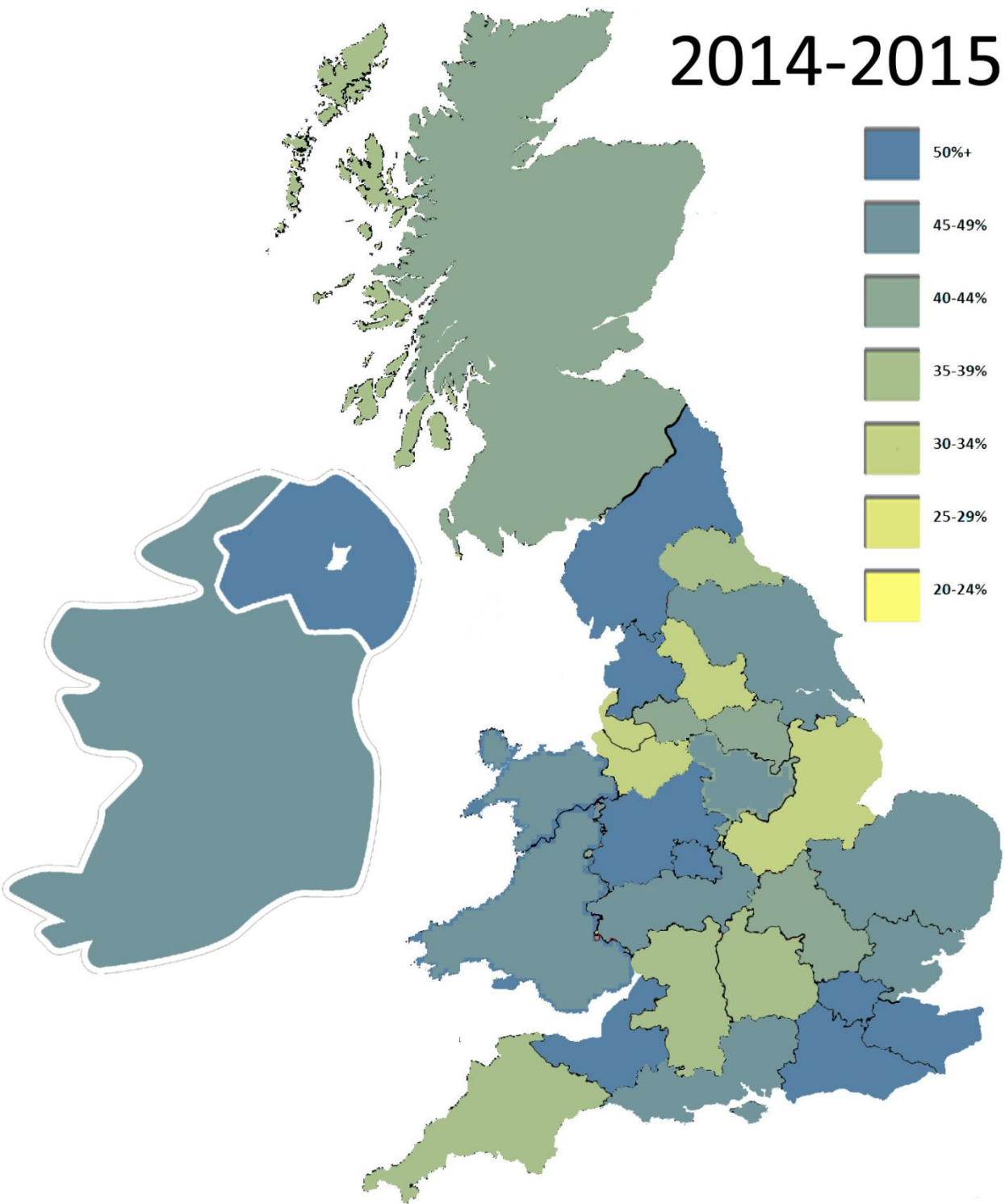
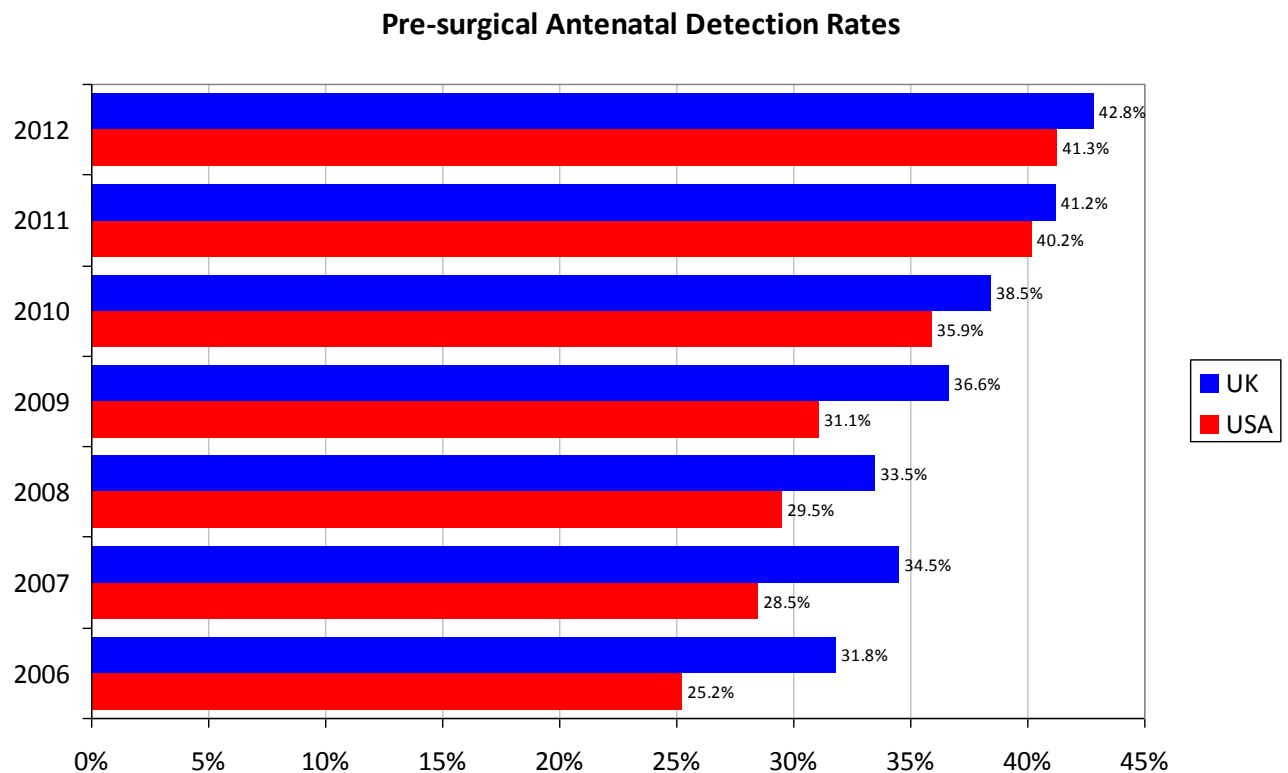


Figure 5: Pre-surgical antenatal detection rates: comparison of UK and USA 2006-2012



The antenatal detection rate in the UK exceeds that in the USA during this 7 year period, based on data published from the USA covering this time period (later data not available)⁹. Note that the US data is based on 91 of the 125 centres (73%) undertaking CHD surgery in the US, and is based on the percentage of infants requiring cardiovascular surgery at under 6 months of age).

⁹ US rates reference: www.pediatrics.org/cgi/doi/10.1542/peds.2014-3783

Variation in Prenatal Diagnosis of Congenital Heart Disease in Infants. Michael D Quartermain et al. PEDIATRICS Volume 136, number 2, August 2015.

5. Next steps for the audit

High quality information is at the heart of improving the quality of Congenital Heart Disease Services. In 2015/16 we are continuing to focus on improving the quality of data to ensure accurate and timely information is readily available to specialist services, commissioners and patients and their families. Our priority areas for 2015-2016 and 2016-17 have been, and are:

- **Adult case ascertainment.**

The Audit is aware that some adult congenital cases treated at non-specialist centres are not submitted to NCHDA. NHS England with help from the NCHDA Clinical Lead have already performed analyses using HES data to ascertain the number of centres and patients whose procedures have not been submitted historically to the Audit. We will take this work further by cross referencing data submitted to the National Adult Cardiac Surgery Audit and National Audit of Percutaneous Coronary Intervention to identify centres undertaking Adult Congenital Heart disease procedures. From 2015/16 non-participating centres will be published in the annual report.

- **Focus on procedural morbidity.**

In 2014, the NCHDA dataset was reviewed to ensure that the data collected continues to be most relevant to improving the quality of patient care and their outcomes. As survival rates have improved over time, more attention needs to be given to other measures of quality, such as post-procedural complications. From April 2015 the NCHDA dataset was updated to support these developments with several additional fields: postoperative and post interventional procedure complications, procedural urgency and documenting if additional procedures are expected or unexpected with respect to the individual patient's management pathway. The audit will continue to use validation visits to ensure data is entered consistently and of high quality by all of the centres, particularly with respect to these additional data fields.

- **Focus on adult congenital heart disease outcomes.**

Although mortality rates for adult CHD patients remain very low, there is a need to develop a risk stratification model which takes into account factors or comorbidities which are specific for adult patients. From April 2015 the NCHDA dataset was updated with new fields to support the eventual development of such a model, including pre-procedural systemic and subpulmonary ventricular function, preprocedural New York Heart Association functional class, smoking status and diabetes status, as well as evidence of preprocedural ischaemic heart disease or pulmonary disease.

- **Monitoring the outcomes of implanted valves and devices.**

It is increasingly recognised that implanted valves and devices may have specific complications that may relate to a particular batch or device model. Data fields have been added to the NCHDA dataset to capture this information (manufacturer, device model, device size and serial number). Monitoring device related outcomes is in line with recommendations from the Medicines & Healthcare products Regulatory Agency.

- **Development of additional measures that can be used to support quality improvement.**

These include:

- **Specific Procedures.**

Further expanding the number of reported specific procedures reported by the audit, if possible.

- **90 days life status for all major cardiac surgical and interventional procedures.**

NCHDA 30 day outcome uses ONS data in parallel with hospital reported discharge outcome linked to individual procedures to confirm life status. This is not applicable at 90 days as almost all cases have been discharged before 90 days and centres are not currently able to report life status except when linked to a

procedure. It has been estimated that 25% of congenital cases are subject to coroner's inquest and the time frame for inquest conclusion can vary between 6 weeks and 2 years. During that period life status will be reported incorrectly by ONS as "alive". In 2013-14 there were 91 discrepancies likely to potentially bias the results. NICOR is seeking approval from the Health and Social Care Information Centre to access information about referred cases before a death certificate has been issued (which must currently await a certified cause of death). In addition we will be enabling centres to enter life status when known independent of a linked procedure. We are investigating the possibility of including this additional outcome measure for the 2015-16 report, if these issues can be resolved.

- **Long term outcome by diagnosis.**

The NCHDA Steering Committee notes the high priority attached to assessment of long term outcomes by diagnosis by stakeholders including, in particular, patient families. The NCHDA Research Committee has supported a current project funded by Great Ormond Street Children's Charity that runs until the end of 2016 and represents a pilot evaluation of the NCHDA data as a means to track long term survival focussed on one very complex diagnosis (hypoplastic left heart syndrome) and one less complex diagnosis (ventricular septal defect). A further funding application to build upon and take forward this pilot work has been submitted to NIHR in early 2016

- **Morbidity measures.**

The NCHDA is closely involved with the NIHR HSDO funded project (Grant 12/5005/06) 'Selection, definition and evaluation of important early morbidities associated with paediatric cardiac surgery <http://www.nets.nihr.ac.uk/projects/hsdr/12500506>. The deliverables of this project will be a guide as to the direction of future morbidity monitoring within the audit, please read the project web pages for further details.

- **Improve the information on antenatal diagnosis and outcome.**

We aim to extend the audit to include an expansion of the antenatal diagnosis fields. Currently this is reported by the specialist centres as part of their audit return with a simple Yes/No response of whether a patient was diagnosed antenatally. Work is underway to secure funding to support this work. The plan is for an additional 12 data fields which will include maternal demographics, fetal CHD and extracardiac diagnoses and fetal outcomes, including termination, still birth and going on to have a postnatal procedure. This dataset would also link to the postnatal NCHDA dataset and would be key to moving towards a diagnosis based database. The initial pilot phase would focus on ten CHD malformations, including hypoplastic left heart syndrome, transposition of the great arteries and atrioventricular septal defect. This expansion is supported by Public Health England, HQIP and NHS England. There are also plans to bidirectionally link to the National Congenital Anomaly and Rare Disease Registration Service (NCARDS) for data validation and case ascertainment purposes.

- **Improving data submission and verification.**

A web enabled version of the data collection system is in development and due to be rolled out and tested in time for full implementation in 2016. The framework being used encompasses modern technologies where it supports multiple browsers, which in turn can be run on PCs or portable devices. As a single code stream that NICOR are moving towards there are a multitude of benefits for the NCHDA database, less effort of familiarisation to the user base submitting data, a single code stream that has the main focus thus driving quality improvement and reduced timelines for new features. In addition a real time data completeness tool highlighting data inconsistency and missing values will give centres immediate instant feedback on the data they have submitted.

- **Improving the NCHDA Public Portal.**

In 2015, we undertook a patient survey to gain feedback on the quality and content of the current audit portal. The main aim was to understand how it is used by patients and their families and what changes would make audit information more accessible. Further work in this area is in progress and improvements can be expected in mid 2016 in how data is displayed, configured and explained on the NCHDA web portal.

6. Recommendations

I. Chief Executives, Medical Directors and Clinical Leads at Provider Centres

We recommend that you:

- Ensure that your Specialist Surgical Centre has a minimum of 1 WTE dedicated paediatric cardiac surgery/cardiology Database Manager, with at least 1 WTE assistant, responsible for audit and database submissions in accordance with necessary timescales. This recommendation is in accordance with the congenital cardiology Standards published as part of the NHS England new CHD review (July 2015).
- Ensure there are sufficient resources allocated to, and sufficient processes put in place to fully support national clinical audit activity, including local IT support and software that fully accommodates the NCHDA dataset for timely submission of data and verification of data quality.
- Ensure all patients undergoing CHD procedures have a preceding congenital cardiology MDT, in accordance with the congenital cardiology Service Specification published as part of the NHS England new CHD Review (2015).
- Provide appropriate clinical support to the clinical audit teams. Our data show that higher level of clinical engagement with the clinical audit team is associated with a better data completeness and data quality. Each clinical audit should have an identified Clinical Audit Lead assigned to support this activity.
- Ensure all operators regularly review their data submitted to the NCHDA to improve timeliness and accuracy (monthly for large centres).
- Engage with the NCHDA annual validation site visit reports, considering and implementing recommendations therein.
- Ensure that all centres undertaking congenital cardiology procedures submit data to the NCHDA, including adult patients with CHD.

II. Congenital Cardiology Clinical Audit Teams

We recommend that you:

- Ensure there are Standard Operating Protocols in place that ensure timely and accurate NCHDA data submissions on at least a quarterly basis, as well as reverse validation of submitted data (monthly for large centres). More contemporaneous data submission is associated with better data completeness and data quality.
- Check that the data submitted to NICOR shows what you expect it to (reverse validation); this is especially relevant to those hospitals that use third party software to submit their data.
- Ensure there are regular meetings between the database manager(s) and Clinical Audit Leads (surgical and interventional catheter) to internally check data quality (monthly for large centres).
- Ensure that those centres undertaking paediatric congenital cardiology operations present and review their internal VLAD plots generated by the PRAiS analyses at monthly congenital cardiology MDT mortality & morbidity meetings, documenting discussions and resulting action points. This is one of the Quality Dashboard metrics submitted to Specialist Commissioners.
- Encourage senior congenital cardiology trainees (ST6-7) to be actively involved in the NCHDA process and volunteer to be an assisting clinician on at least one external validation visit prior to seeking a Consultant post.

III. Patients and Public

- This report, along with the NCHDA web Portal, allows you to review of activity of local centres as well outcomes such as survival following major procedures. It provides comparison of risk adjusted mortality between paediatric centres, identifies alerts and alarms and responses from centres.

Appendices

Appendix 1. 30 day outcomes by age group for all procedures and for specific procedures

Table of procedures undertaken for paediatric and congenital heart disease for from April 2012 to March 2015 inclusive. There are 73 distinct specific procedures (84.8%) reported, along with a summation of the 15.2% of miscellaneous procedures reported with low individual procedure frequency. Please note that this is a listing of procedures undertaken at different ages. It does not equate to the number of patients, as a proportion of patients will have had more than one procedure during this three year period.

More information is available on the NCHDA website:

https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Interpreting%20the%20latest%20data%20analyses%20on%20this%20website?Opendocument

	ALL AGES					Paediatric (aged <16)					Adult Congenital (Age >=16)				
	Total	Alive	Dead	Unknown	30d mortality	Total	Alive	Dead	Unknown	30d mortality	Total	Alive	Dead	Unknown	30d mortality
All Procedures	30,995	30,373	597	25	1.9%	22,338	21,809	516	13	2.3%	8,657	8,564	81	12	1.0%
bypass	13,986	13,641	340	5	2.4%	13,986	10,453	278	3	2.6%	3,252	3,188	62	2	1.9%
non-bypass	3,343	3,236	105	2	3.1%	3,156	3,051	103	2	3.3%	187	185	2	0	1.1%
catheter	13,539	13,382	141	16	1.0%	8,328	8,198	124	6	1.5%	5,211	5,184	17	10	0.3%
hybrid	127	114	11	2	8.8%	120	107	11	2	9.3%	7	7	0	0	0.0%
Specific Procedure															
no specific procedure allocated (15.1%)	4,678	4,516	159	3	3.4%	3,492	3,347	142	3	4.1%	1,186	1,169	17	0	1.4%
all specific procedures (84.9%)	26,317	25,857	438	22	1.7%	18,846	18,462	374	10	2.0%	7,471	7,395	64	12	0.9%
Surgical															
Anomalous coronary artery repair	53	52	0	1	0.0%	41	41	0	0	0.0%	12	11	0	1	0.0%
Aortic root replacement (not Ross)	213	206	7	0	3.3%	31	30	1	0	3.2%	182	176	6	0	3.3%
Aortic valve repair	268	263	5	0	1.9%	198	194	4	0	2.0%	70	69	1	0	1.4%
Aortic Valve Replacement - non Ross	534	518	14	2	2.6%	52	50	2	0	3.8%	482	468	12	2	2.5%
Aortic valve replacement - Ross	150	150	0	0	0.0%	82	82	0	0	0.0%	68	68	0	0	0.0%
Aortopulmonary window repair	26	26	0	0	0.0%	26	26	0	0	0.0%	0	0	0	0	
Arterial shunt	391	359	31	1	7.9%	389	357	31	1	8.0%	2	2	0	0	0.0%
Arterial switch (for isolated transposition)	405	398	6	1	1.5%	405	398	6	1	1.5%	0	0	0	0	
Arterial switch + aortic arch obstruction repair (with-without VSD closure)	63	54	9	0	14.3%	63	54	9	0	14.3%	0	0	0	0	
Arterial switch + VSD closure	176	171	5	0	2.8%	176	171	5	0	2.8%	0	0	0	0	
ASD repair	872	871	1	0	0.1%	592	592	0	0	0.0%	280	279	1	0	0.4%
Atrioventricular septal defect and tetralogy repair	38	37	1	0	2.6%	37	36	1	0	2.7%	1	1	0	0	0.0%
Atrioventricular septal defect (complete) repair	536	532	4	0	0.7%	529	525	4	0	0.8%	7	7	0	0	0.0%

Atrioventricular septal defect (partial) repair	277	276	1	0	0.4%	220	219	1	0	0.5%	57	57	0	0	0.0%
Bidirectional cavopulmonary shunt	705	694	11	0	1.6%	692	684	8	0	1.2%	13	10	3	0	23.1%
Cardiac conduit replacement	166	162	4	0	2.4%	128	124	4	0	3.1%	38	38	0	0	0.0%
Cor triatriatum repair	41	40	1	0	2.4%	36	35	1	0	2.8%	5	5	0	0	0.0%
Fontan procedure	665	658	7	0	1.1%	655	648	7	0	1.1%	10	10	0	0	0.0%
Heart Transplant	119	112	7	0	5.9%	87	84	3	0	3.4%	32	28	4	0	12.5%
Interrupted aortic arch repair	70	69	1	0	1.4%	70	69	1	0	1.4%	0	0	0	0	
Isolated coarctation/ hypoplastic aortic arch repair	795	781	13	1	1.6%	772	759	12	1	1.6%	23	22	1	0	4.3%
Isolated Pulmonary artery band	355	347	8	0	2.3%	353	345	8	0	2.3%	2	2	0	0	0.0%
Isolated RV to PA conduit construction	357	346	11	0	3.1%	297	287	10	0	3.4%	60	59	1	0	1.7%
Mitral valve repair	255	249	6	0	2.4%	168	165	3	0	1.8%	87	84	3	0	3.4%
Mitral valve replacement	228	213	15	0	6.6%	122	111	11	0	9.0%	106	102	4	0	3.8%
Multiple VSD Closure	43	43	0	0	0.0%	43	43	0	0	0.0%	0	0	0	0	
Norwood procedure (Stage 1)	350	310	40	0	11.4%	350	310	40	0	11.4%	0	0	0	0	
PDA ligation (surgical)	1,003	964	39	0	3.9%	1,003	964	39	0	3.9%	0	0	0	0	
Pulmonary atresia VSD repair	113	111	2	0	1.8%	113	111	2	0	1.8%	0	0	0	0	
Pulmonary valve replacement	928	920	7	1	0.8%	195	194	1	0	0.5%	733	726	6	1	0.8%
Pulmonary vein stenosis procedure	78	72	6	0	7.7%	63	57	6	0	9.5%	15	15	0	0	0.0%
Rastelli - REV procedure	61	59	2	0	3.3%	61	59	2	0	3.3%	0	0	0	0	
Repair of total anomalous pulmonary venous connection	208	197	11	0	5.3%	205	194	11	0	5.4%	3	3	0	0	0.0%
Ross-Konno procedure	59	55	4	0	7.3%	51	47	4	0	7.8%	8	8	0	0	0.0%
Senning or Mustard procedure	7	6	1	0	14.3%	7	6	1	0	14.3%	0	0	0	0	
Sinus Venosus ASD and-or PAPVC repair	349	346	2	1	0.6%	166	163	2	1	1.2%	183	183	0	0	0.0%
Subvalvar aortic stenosis repair	513	511	2	0	0.4%	408	407	1	0	0.2%	105	104	1	0	1.0%
Supravalvar aortic stenosis repair	71	70	1	0	1.4%	64	63	1	0	1.6%	7	7	0	0	0.0%
TAPVC Repair + Arterial Shunt	5	2	3	0	60.0%	5	2	3	0	60.0%	0	0	0	0	
Tetralogy and Fallot-type DORV repair	939	934	5	0	0.5%	933	928	5	0	0.5%	6	6	0	0	0.0%
Tetralogy with absent pulmonary valve repair	27	26	1	0	3.7%	27	26	1	0	3.7%	0	0	0	0	
Tricuspid valve repair	205	196	9	0	4.4%	88	82	6	0	6.8%	117	114	3	0	2.6%
Tricuspid valve replacement	111	107	4	0	3.6%	16	14	2	0	12.5%	95	93	2	0	2.1%
Truncus and interruption repair	10	9	1	0	10.0%	10	9	1	0	10.0%	0	0	0	0	
Truncus arteriosus repair	91	85	6	0	6.6%	91	85	6	0	6.6%	0	0	0	0	
Unifocalisation procedure (with/without shunt)	37	34	3	0	8.1%	37	34	3	0	8.1%	0	0	0	0	
Vascular ring procedure	190	187	3	0	1.6%	186	183	3	0	1.6%	4	4	0	0	0.0%
VSD Repair	1,022	1,018	4	0	0.4%	993	989	4	0	0.4%	29	29	0	0	0.0%

Interventional

ASD closure (catheter)	2,008	2,004	1	3	0.0%	766	765	0	1	0.0%	1,242	1,239	1	2	0.1%
Balloon atrial septostomy	509	470	39	0	7.7%	504	467	37	0	7.3%	5	3	2	0	40.0%
Balloon dilation native coarctation	70	69	1	0	1.4%	65	64	1	0	1.5%	5	5	0	0	0.0%
Balloon Dilation of Aortic Valve	318	312	6	0	1.9%	301	296	5	0	1.7%	17	16	1	0	5.9%
Balloon Dilation of Pulmonary Artery	659	651	7	1	1.1%	615	607	7	1	1.1%	44	44	0	0	0.0%
Balloon Dilation of Pulmonary Valve	695	688	6	1	0.9%	624	617	6	1	1.0%	71	71	0	0	0.0%
Biventricular pacing and CRT	41	41	0	0	0.0%	2	2	0	0	0.0%	39	39	0	0	0.0%
Blade atrial septostomy	8	6	2	0	25.0%	7	5	2	0	28.6%	1	1	0	0	0.0%
Cardiac conduit balloon dilation or stenting	136	134	2	0	1.5%	104	104	0	0	0.0%	32	30	2	0	6.3%
Coarctation stenting	371	369	2	0	0.5%	139	138	1	0	0.7%	232	231	1	0	0.4%
Duct Stenting	81	73	8	0	9.9%	77	69	8	0	10.4%	4	4	0	0	0.0%
Implantable Cardioverter Defibrillator	209	209	0	0	0.0%	69	69	0	0	0.0%	140	140	0	0	0.0%
Pacemaker implant	610	609	0	1	0.0%	304	304	0	0	0.0%	306	305	0	1	0.0%
PDA closure (catheter)	1,812	1,808	3	1	0.2%	1,713	1,709	3	1	0.2%	99	99	0	0	0.0%
PFO closure (catheter)	1,390	1,386	4	0	0.3%	20	20	0	0	0.0%	1,370	1,366	4	0	0.3%
Pulmonary artery stenting	471	463	7	1	1.5%	393	385	7	1	1.8%	78	78	0	0	0.0%
Pulmonary valvotomy (radiofrequency)	81	79	2	0	2.5%	81	79	2	0	2.5%	0	0	0	0	
Pulmonary vein catheter procedure	63	59	4	0	6.3%	52	48	4	0	7.7%	11	11	0	0	0.0%
Radiofrequency ablation for tachyarrhythmia	1,808	1,802	1	5	0.1%	1,095	1,094	0	1	0.0%	713	708	1	4	0.1%
Recoarctation angioplasty	239	237	2	0	0.8%	214	212	2	0	0.9%	25	25	0	0	0.0%
RVOT Stenting	135	128	7	0	5.2%	121	114	7	0	5.8%	14	14	0	0	0.0%
Systemic-to-pulmonary collateral artery (MAPCA) related catheter procedure	152	147	5	0	3.3%	145	140	5	0	3.4%	7	7	0	0	0.0%
Transcatheter PVR	183	180	2	1	1.1%	36	36	0	0	0.0%	147	144	2	1	1.4%
VSD closure (catheter)	90	87	3	0	3.3%	63	62	1	0	1.6%	27	25	2	0	7.4%

Appendix 2 Outcomes based research using NCHDA data

Outcomes based research	<p>Brown KL, Crowe S, Franklin R, McLean A, Cunningham D, Barron D, Tsang V, Pagel C, Utley M. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. Open Heart 2015;2:e000157. doi:10.1136/openhrt-2014-000157</p> <p>This study demonstrates that deaths within 30 days of children's heart surgery have almost halved over the past decade, despite a rise in the proportion of more complex and high risk cases during that period. The analyses include the data submitted to NCHDA for all children under 16 between 2000 and 2010 inclusive. This represents a total of 36,641 episodes of surgery, corresponding to 30,041 individual patients, with 5142 undergoing two or more surgical episodes in the period covered by the data. In 4.4% of the episodes, the patient had another operation within 30 days.</p> <p>The annual number of episodes rose between 2000 and 2009 from 2283 to 3939 and the 30 day death rate fell consistently from 4.3% of cases to 2.6%. This was despite an increase in the proportion of more complex and higher risk cases. These figures, suggest that rather than turning away higher risk patients during an era when outcomes have been monitored closely, a greater proportion of more complex patients were taken on, 30 day death rates for children's heart surgery in the UK are low, falling and compare well with similar data from other, international databases.</p> <p>The very low mortality rates at 30 days must shift our focus now towards measures of morbidity, longer term survival 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 long term benefits of different surgical strategies and models of care.</p> <p>The funder for this research project was Great Ormond Street Children's Charity Grant V1248</p>
	<p>Infant deaths in the UK community following successful cardiac surgery - building the evidence base for optimal surveillance: mixed methods study (The Infant Heart Study)</p> <p>Primary Investigator: Dr Kate Brown, Great Ormond Street</p> <p>In recent years outcomes for children's heart surgery have greatly improved, largely due to better management in hospital. However, after hospital discharge some babies die unexpectedly or require emergency readmission to intensive care. The "Infant Heart Study" (http://www.nets.nihr.ac.uk/projects/hsdr/10200229) aimed to explore risk factors for poor outcomes after hospital discharge for infants undergoing heart surgery, to understand how the health system works for them after discharge and to propose interventions to improve outcomes. The Infant Heart Study used a range of different methods to collect data: we identified relevant published literature; analysed national audit data routinely collected about UK babies undergoing heart surgery or admitted to intensive care; and conducted interviews with parents of children who had died or been readmitted unexpectedly after hospital discharge, health professionals who work with these babies in hospitals or the community, and charity help-line staff. A group of people from different backgrounds was convened to suggest effective interventions. Results indicate the need for: improved discharge</p>

	<p>planning and communication between professionals in specialist hospital, local hospital and community settings caring for infants discharged after heart surgery; infants identified as being at high risk to be discharged from the specialist hospital to their local hospital before going home; a home-monitoring programme for infants at high risk; clear guidance to families and health professionals about spotting early warning signs in a baby who has had heart surgery; standardised training and information for families prior to discharge; and the opportunity for families to seek peer support from other families through charity-based groups or social media.</p> <p>This project was funded by the National Institute for Health Research Health Services and Delivery Research programme (Project No: 10/2002/29). The study webpages, which include the 'First Look' Scientific Summary, may be found at:</p> <p>Real time monitoring of risk-adjusted paediatric cardiac surgery outcomes using variable life-adjusted display: implementation in three UK centres. Pagel C, Utley M, Crowe S, Witter T, Anderson D, Samson R, McLean A, Banks V, Tsang V, Brown K. Heart. 2013 Apr 5.</p> <p>The PRAiS (Partial Risk Adjustment in Surgery) risk model is an excellent example of how clinical audit and research activities contribute to quality improvement. Estimating the risk of death is complex and needs to take into account a wide range of factors such as the complexity of the procedure, diagnosis, age and weight. This is especially difficult for congenital heart disease because the case mix for paediatric cardiac surgery is complex. The PRAiS risk model was developed with Funding by NIHR HSR (Grant 09/2001/13) by the Clinical Outcomes Research Unit (CORU) at UCL and clinicians at Great Ormond Street Hospital in conjunction with members of the NCHDA Steering Committee, using national congenital audit data. Following on from risk model development, the PRAiS based variable life adjusted display (VLAD) software was developed by CORU at UCL, and allows UK and Republic of Ireland congenital cardiac surgeons, cardiac centres and the NCHDA to routinely monitor the contemporary short term surgical outcomes of their patients. The software generates estimates of risk for all 30 day episodes of care and produces a VLAD chart covering the period of the data under review. VLAD charts allow units to quickly identify trends in outcomes (positive or negative) that might warrant further investigation. With NICOR support, the software is now used by all specialist hospitals to help monitor patient outcomes and improve patient care. CORU, and clinicians from the NCHDA Steering Committee are in the process of updating the risk adjustment model with further funding from NIHRHSDO (Grant 14/19/13) and this will be implemented in 2017.</p> <p>Prenatal screening for major congenital heart disease: assessing performance by combining national cardiac audit with maternity data. Gardiner HM1, Kovacevic A, van der Heijden LB, Pfeiffer PW, Franklin RC, Gibbs JL, Averiss IE, Larovere JM. Heart. 2014 Mar;100(5):375-82. doi: 10.1136/heartjnl-2013-304640. Epub 2013 Nov 22</p> <p>Poor antenatal diagnosis rates reduce the opportunity for a comprehensive fetal examination, pregnancy counselling, and the best care for infants following delivery. Failure to recognize and promptly treat major congenital heart disease is associated with increases in morbidities and mortality rates and is recognized as an important quality-of-care issue. In this study, maternity screening ultrasound data was linked with audit antenatal diagnosis and intervention data, and compared 3 maternity hospitals that had different levels of access to specialist advice, training and audit feedback. The hospital with highest detection rates was the one colocated within a specialist fetal medicine unit, with ready access to second opinion; a proactive superintendent; and received on-site training and regular audit feedback. The positive results were likely due to a cardiologist on staff providing easy access to expert second opinion and enhanced training opportunities from the high number of CHD referrals. This study has recommended that maternal information is also collected within the NICOR congenital dataset to enable mother and infant linkage and tracking, so that training can be targets at centres that need it most.</p>
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Appendix 3. Data Quality Index for the 34 centres undertaking CHD procedures in UK and RoI

Code	DQI% 2012-13			DQI% 2013-14			DQI% 2014-15		
	Overall	Surgery	Interventional	Overall	Surgery	Interventional	Overall	Surgery	Interventional
ACH	96.0	96.0	92.8	94.8	96.0	92.3	97.3	96.5	98.0
BCH	98.0	98.0	98.0	96.5	96.8	97.0	98.5	98.5	98.0
BRC	91.8	87.0	96.5	96.5	98.3	93.3	94.5	95.0	94.0
FRE	98.0	97.0	99.0	96.8	97.3	95.5	97.3	97.3	97.0
GOS	99.0	98.3	98.0	99.5	99.5	99.5	99.5	99.5	99.5
GRL	94.0	95.8	90.0	90.5	94.0	85.5	94.0	92.5	97.0
GUY	97.0	97.5	96.5	97.0	98.0	94.3	97.5	98.5	98.0
HSC	95.0	94.8	96.0	95.8	96.5	94.5	94.5	96.5	86.0
LGI	94.8	94.3	96.0	97.8	95.3	99.0	97.0	97.3	96.0
NHB	97.0	97.9	96.4	98.0	99.3	96.3	99.0	98.8	97.8
OLS	95.5	97.0	94.0	96.5	96.3	96.5	97.3	97.3	96.0
RHS	98.5	99.0	99.0	98.5	97.5	99.5	98.5	99.5	95.5
RVB	98.2	98.1	98.5	95.8	96.8	95.3	98.8	99.8	98.3
SGH	96.5	98.8	99.8	98.0	98.3	98.3	97.5	98.0	97.5
BAS	not visited - insufficient procedures			Remote validation			Remote validation		
BHL	97.5	n/a	97.5	Remote validation			Remote validation		
CHN	68.8	n/a	68.8	Remote validation			Remote validation		
GEO	90.8	90.0	91.0	Remote validation			Remote validation		
GHB	not visited - insufficient procedures			not validated - insufficient procedures			not validated - insufficient procedures		
GJH	94.0	93.0	97.8	97.5	98.5	95.3	94.5	95.2	94.0
HAM	90.0	n/a	90.0	Remote validation			Remote validation		
KCH	85.0	n/a	85.0	Remote validation			Remote validation		
MOR	not visited - insufficient procedures			not validated - insufficient procedures			not validated - insufficient procedures		
MRI	93.5	93.8	93.0	95.0	97.8	92.3	97.0	97.3	96.0
NCR	not visited - insufficient procedures			not validated - insufficient procedures			not validated - insufficient procedures		
NGS	94.0	94.8	93.3	Remote validation			Remote validation		
QEB	90.0	89.0	90.0	77.0	82.3	79.8	79.0	77.0	87.5
RAD	92.5	n/a	92.5	Remote validation			Remote validation		
RSC	90.5	n/a	n/a	Remote validation			Remote validation		
STO	82.5	n/a	n/a	Remote validation			Remote validation		
UCL	94.3	96.5	93.5	89.5	89.0	88.8	94.3	93.5	95.3
UHW	82.5	72.5	87.3	Remote validation			Remote validation		
VIC	not visited - insufficient procedures			not validated - insufficient procedures			not validated - insufficient procedures		
WAL	not visited - insufficient procedures			not validated - insufficient procedures			not validated - insufficient procedures		

STH	97.8	n/a	97.8	Unified with Evelina Children 's Hospital	Unified with Evelina Children 's Hospital
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Key to Hospital codes:

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

Appendix 4. Rates of antenatal detection by country

Country	2010-11	2011-12	2012-13	2013-14	2014-15
England	38.1%	40.0%	42.5%	46.9%	47.1%
Ireland (RoI)	21.8%	37.0%	32.6%	38.1%	49.3%
N Ireland	31.6%	36.0%	33.8%	38.6%	50.0%
Scotland	29.7%	37.3%	46.6%	37.6%	44.9%
Wales	47.3%	60.9%	56.1%	54.7%	49.4%
UK and RoI (overall)	36.1%	40.3%	42.2%	45.7%	47.3%