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. HQIP’s aim is to promote quality improvement and is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices.

The Clinical Outcome Review Programmes, which encompasses confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness’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.

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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 budget. 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

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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 in line with the Office for National Statistics Confidentiality Guidance for publishing health statistics.

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 portal.

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:

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

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 adulthood. 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.

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.

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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>
<thead>
<tr>
<th>Table 1: Extended use of audit data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality improvement activity</strong></td>
</tr>
<tr>
<td>Local audit and Quality Dashboards for Specialist Commissioning</td>
</tr>
<tr>
<td>NHS England Service Review</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>CQC data flows</td>
</tr>
<tr>
<td>Outcomes based research</td>
</tr>
</tbody>
</table>

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>
<thead>
<tr>
<th>Hospital undertaking Paediatric and ACHD procedures</th>
<th>Code</th>
<th>Number of procedures: Total (Paediatric/Adult cases)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liverpool, Alder Hey Hospital</td>
<td>ACH</td>
<td>1893 (1838/55)</td>
</tr>
<tr>
<td>Birmingham Children’s Hospital</td>
<td>BCH</td>
<td>2805 (2686/119)</td>
</tr>
<tr>
<td>Bristol Royal Hospital For Children</td>
<td>BRC</td>
<td>2273 (1515/758)</td>
</tr>
<tr>
<td>Newcastle, Freeman Hospital</td>
<td>FRE</td>
<td>1507 (1106/401)</td>
</tr>
<tr>
<td>London, Great Ormond Street Hospital for Children</td>
<td>GOS</td>
<td>3109 (2995/114)</td>
</tr>
<tr>
<td>Leicester, Glenfield Hospital</td>
<td>GRL</td>
<td>1534 (1101/433)</td>
</tr>
<tr>
<td>London, Evelina London Children’s &amp; St Thomas Hospitals</td>
<td>GUY</td>
<td>2578 (1956/622)</td>
</tr>
<tr>
<td>London, Harley Street Clinic</td>
<td>HSC</td>
<td>695 (591/104)</td>
</tr>
<tr>
<td>Leeds General Infirmary</td>
<td>LGI</td>
<td>2421 (1690/731)</td>
</tr>
<tr>
<td>London, Royal Brompton Hospital</td>
<td>NHB</td>
<td>2782 (1941/841)</td>
</tr>
<tr>
<td>Dublin, Our Lady’s Children’s Hospital</td>
<td>OLS</td>
<td>1891 (1857/34)</td>
</tr>
<tr>
<td>Oxford, John Radcliffe Hospital</td>
<td>RAD</td>
<td>321 (20/301)</td>
</tr>
<tr>
<td>Glasgow, Royal Hospital for Sick Children</td>
<td>RHS</td>
<td>1346 (1315/31)</td>
</tr>
<tr>
<td>Belfast, Royal Victoria Hospital</td>
<td>RVB</td>
<td>583 (302/281)</td>
</tr>
<tr>
<td>Southampton General Hospital</td>
<td>SGH</td>
<td>1911 (1423/488)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hospital undertaking only Adult CHD procedures</th>
<th>Code</th>
<th>Number of procedures: Total (paediatric/ACHD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI The Alexandra Hospital</td>
<td>AHM</td>
<td>3 (0/3)</td>
</tr>
<tr>
<td>Basildon, Essex Cardiothoracic Centre</td>
<td>BAS</td>
<td>9 (0/9)</td>
</tr>
<tr>
<td>Liverpool Heart and Chest Hospital</td>
<td>BHL</td>
<td>428 (1/427)</td>
</tr>
<tr>
<td>Nottingham City Hospital</td>
<td>CHN</td>
<td>87 (0/87)</td>
</tr>
<tr>
<td>London, St George’s Hospital</td>
<td>GEO</td>
<td>103 (0/103)</td>
</tr>
</tbody>
</table>
### Table 3: inclusion criteria for each analysis

<table>
<thead>
<tr>
<th>Analyses</th>
<th>Years</th>
<th>Age group</th>
<th>Inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk adjusted: outcome at 30 days after procedure.</td>
<td>2012/15</td>
<td>Under 16 years</td>
<td>All surgical procedures (risk adjusted)</td>
</tr>
<tr>
<td>Specific procedures: outcome at 30 days after procedure</td>
<td>2012/15</td>
<td>1. Under 16 years</td>
<td>2. 16 years and over</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>All surgical and interventional procedures for congenital heart disease</td>
</tr>
</tbody>
</table>

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](http://www.ucl.ac.uk/nicor/audits/congenital/datasets), and in Appendix 1. The website also provides information on the procedures undertaken at each of the centres.

### 3.3. Coding


### 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 greater 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 is in line with the Office for National Statistics Confidentiality Guidance for publishing health statistics.

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

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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

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

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

<table>
<thead>
<tr>
<th>Type</th>
<th>Provider</th>
<th>Paediatric</th>
<th>Adult</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interventional</td>
<td>England</td>
<td>6,713</td>
<td>4,749</td>
<td>11,478</td>
</tr>
<tr>
<td>Interventional</td>
<td>N Ireland</td>
<td>160</td>
<td>189</td>
<td>349</td>
</tr>
<tr>
<td>Interventional</td>
<td>Private</td>
<td>149</td>
<td>48</td>
<td>197</td>
</tr>
<tr>
<td>Interventional</td>
<td>RoI</td>
<td>801</td>
<td>29</td>
<td>830</td>
</tr>
<tr>
<td>Interventional</td>
<td>Scotland</td>
<td>505</td>
<td>128</td>
<td>633</td>
</tr>
<tr>
<td>Interventional</td>
<td>Wales</td>
<td>0</td>
<td>52</td>
<td>52</td>
</tr>
<tr>
<td>Surgical</td>
<td>England</td>
<td>11,560</td>
<td>2,896</td>
<td>14,456</td>
</tr>
<tr>
<td>Surgical</td>
<td>N Ireland</td>
<td>142</td>
<td>92</td>
<td>234</td>
</tr>
<tr>
<td>Surgical</td>
<td>Private</td>
<td>442</td>
<td>60</td>
<td>502</td>
</tr>
<tr>
<td>Surgical</td>
<td>RoI</td>
<td>1,056</td>
<td>5</td>
<td>1,061</td>
</tr>
</tbody>
</table>
### Table 6: Total number of cases submitted to the audit by financial year

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

#### 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 website. 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](https://nicor4.nicor.org.uk/chd/an_paeds.nsf/vwContent/Data%20Quality%20Reports?OpenDocument)

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

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

% successfully diagnosed antenatally
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
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). 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).

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


<table>
<thead>
<tr>
<th>All Procedures</th>
<th>Total</th>
<th>Alive</th>
<th>Dead</th>
<th>Unknown</th>
<th>30d mortality</th>
<th>Total</th>
<th>Alive</th>
<th>Dead</th>
<th>Unknown</th>
<th>30d mortality</th>
<th>Total</th>
<th>Alive</th>
<th>Dead</th>
<th>Unknown</th>
<th>30d mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Ages</td>
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<td>597</td>
<td>25</td>
<td>1.9%</td>
<td>22,338</td>
<td>21,809</td>
<td>516</td>
<td>13</td>
<td>2.3%</td>
<td>8,657</td>
<td>8,564</td>
<td>81</td>
<td>12</td>
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</tr>
<tr>
<td>Paediatric (aged &lt;16)</td>
<td>13,986</td>
<td>13,641</td>
<td>340</td>
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<td>13,986</td>
<td>10,453</td>
<td>278</td>
<td>3</td>
<td>2.6%</td>
<td>3,252</td>
<td>3,188</td>
<td>62</td>
<td>2</td>
<td>1.9%</td>
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<tr>
<td>Adult Congenital (Age &gt;=16)</td>
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<td></td>
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<td>16,032</td>
<td>1</td>
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<td>16,032</td>
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<tr>
<td>bypass</td>
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<td>4,516</td>
<td>159</td>
<td>3</td>
<td>3.4%</td>
<td>3,492</td>
<td>3,347</td>
<td>142</td>
<td>3</td>
<td>4.1%</td>
<td>1,186</td>
<td>1,169</td>
<td>17</td>
<td>0</td>
<td>1.4%</td>
</tr>
<tr>
<td>Specific Procedure</td>
<td>26,317</td>
<td>25,857</td>
<td>438</td>
<td>22</td>
<td>1.7%</td>
<td>18,846</td>
<td>18,462</td>
<td>374</td>
<td>10</td>
<td>2.0%</td>
<td>7,471</td>
<td>7,395</td>
<td>64</td>
<td>12</td>
<td>0.9%</td>
</tr>
<tr>
<td>Specific Procedure</td>
<td>4,678</td>
<td>4,516</td>
<td>159</td>
<td>3</td>
<td>3.4%</td>
<td>3,492</td>
<td>3,347</td>
<td>142</td>
<td>3</td>
<td>4.1%</td>
<td>1,186</td>
<td>1,169</td>
<td>17</td>
<td>0</td>
<td>1.4%</td>
</tr>
<tr>
<td>Specific Procedure</td>
<td>26,317</td>
<td>25,857</td>
<td>438</td>
<td>22</td>
<td>1.7%</td>
<td>18,846</td>
<td>18,462</td>
<td>374</td>
<td>10</td>
<td>2.0%</td>
<td>7,471</td>
<td>7,395</td>
<td>64</td>
<td>12</td>
<td>0.9%</td>
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<tr>
<td>Surgical</td>
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<td>1</td>
<td>0.0%</td>
<td>41</td>
<td>41</td>
<td>0</td>
<td>0</td>
<td>0.0%</td>
<td>12</td>
<td>11</td>
<td>0</td>
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<tr>
<td>Anomalous coronary artery repair</td>
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<td>31</td>
<td>30</td>
<td>1</td>
<td>0</td>
<td>3.2%</td>
<td>182</td>
<td>176</td>
<td>6</td>
<td>0</td>
<td>3.3%</td>
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<tr>
<td>Aortic root replacement (not Ross)</td>
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<td>263</td>
<td>5</td>
<td>0</td>
<td>1.9%</td>
<td>198</td>
<td>194</td>
<td>4</td>
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<tr>
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<td>518</td>
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<td>0</td>
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<td>482</td>
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<td>150</td>
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<td>82</td>
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<td>0</td>
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<tr>
<td>Aortic valve replacement - Ross</td>
<td>26</td>
<td>26</td>
<td>0</td>
<td>0</td>
<td>0.0%</td>
<td>26</td>
<td>26</td>
<td>0</td>
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<tr>
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<td>389</td>
<td>357</td>
<td>31</td>
<td>1</td>
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<td>398</td>
<td>6</td>
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<td>1.5%</td>
<td>405</td>
<td>398</td>
<td>6</td>
<td>1</td>
<td>1.5%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<tr>
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<td>9</td>
<td>0</td>
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<td>63</td>
<td>54</td>
<td>9</td>
<td>0</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Arterial switch + aortic arch obstruction repair (with-out VSD closure)</td>
<td>176</td>
<td>171</td>
<td>5</td>
<td>0</td>
<td>2.8%</td>
<td>176</td>
<td>171</td>
<td>5</td>
<td>0</td>
<td>2.8%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<td>592</td>
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<td>0</td>
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<td>280</td>
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<td>2.7%</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Atrioventricular septal defect and tetralogy repair</td>
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<td>532</td>
<td>4</td>
<td>0</td>
<td>0.7%</td>
<td>529</td>
<td>525</td>
<td>4</td>
<td>0</td>
<td>0.8%</td>
<td>7</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>0.0%</td>
</tr>
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</table>
VSD Repair
Bidirectional cavopulmonary shunt
Cardiac conduit replacement
Cor triatriatum repair
Fontan procedure
Heart Transplant
Interrupted aortic arch repair
Isolated coarctation/ hypoplastic aortic arch repair
Isolated Pulmonary artery band
Isolated RV to PA conduit construction
Heart Transplant
Fontan procedure
Cor triatriatum repair
Bidirectional cavopulmonary shunt
Atrioventricular septal defect (partial) repair
Tetralogy and Fallot
PDA ligation (surgical)
Norwood procedure (Stage 1)
PDA ligation (surgical)
Pulmonary atresia VSD repair
Pulmonary vein stenosis procedure
Sinus Venous ASD and or PAPVC repair
Rastelli - REV procedure
Repair of total anomalous pulmonary venous connection
Ross-Konno procedure
Senning or Mustard procedure
Sinus Venosus ASD and-or PAPVC repair
Subvalvar aortic stenosis repair
Supravalvar aortic stenosis repair
TAPVC Repair + Arterial Shunt
Tetralogy and Fallot-type DORV repair
Tetralogy with absent pulmonary valve repair
Tricuspid valve repair
Tricuspid valve replacement
Truncus and interruption repair
Truncus arteriosus repair
Unifocalisation procedure (with/without shunt)
Vascular ring procedure
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% 41 41 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 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 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%
### Outcomes based research using NCHDA data

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>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. 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. 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.</td>
</tr>
<tr>
<td>Infant deaths in the UK community following successful cardiac surgery - building the evidence base for optimal surveillance: mixed methods study (The Infant Heart Study)</td>
</tr>
<tr>
<td>Primary Investigator: Dr Kate Brown, Great Ormond Street</td>
</tr>
<tr>
<td>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” (<a href="http://www.nets.nihr.ac.uk/projects/hdrdr/10200229">http://www.nets.nihr.ac.uk/projects/hdrdr/10200229</a>) 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</td>
</tr>
</tbody>
</table>
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.

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:


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 NIHR HSRDO (Grant 14/19/13) and this will be implemented in 2017.

Prenatal screening for major congenital heart disease: assessing performance by combining national cardiac audit with maternity data.

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.
### Appendix 3. Data Quality Index for the 34 centres undertaking CHD procedures in UK and RoI

<table>
<thead>
<tr>
<th>Code</th>
<th>Overall</th>
<th>Surgery</th>
<th>Interventiona</th>
<th>Overall</th>
<th>Surgery</th>
<th>Interventiona</th>
<th>Overall</th>
<th>Surgery</th>
<th>Interventiona</th>
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</thead>
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<tr>
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<td>97.3</td>
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<td>99.0</td>
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<td>99.5</td>
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<td>98.3</td>
<td>97.5</td>
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</table>

**Notes:**
- BAS: not visited - insufficient procedures
- BHL: 97.5 n/a 97.5
- CHN: 68.8 n/a 68.8
- GEO: 90.8 90.0 91.0
- GHB: not visited - insufficient procedures
- GJH: 94.0 93.0 97.8
- HAM: 90.0 n/a 90.0
- KCH: 85.0 n/a 85.0
- MOR: not visited - insufficient procedures
- MRI: 93.5 93.8 93.0
- NCR: not visited - insufficient procedures
- NGS: 94.0 94.8 93.3
- QEB: 90.0 89.0 90.0
- RAD: 92.5 n/a 92.5
- RSC: 90.5 n/a n/a
- STO: 82.5 n/a n/a
- UCL: 94.3 96.5 93.5
- UHW: 82.5 72.5 87.3
- VIC: not visited - insufficient procedures
- WAL: not visited - insufficient procedures

**Remote validation**

Remote validation
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

<table>
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</thead>
<tbody>
<tr>
<td>England</td>
<td>38.1%</td>
<td>40.0%</td>
<td>42.5%</td>
<td>46.9%</td>
<td>47.1%</td>
</tr>
<tr>
<td>Ireland (RoI)</td>
<td>21.8%</td>
<td>37.0%</td>
<td>32.6%</td>
<td>38.1%</td>
<td>49.3%</td>
</tr>
<tr>
<td>N Ireland</td>
<td>31.6%</td>
<td>36.0%</td>
<td>33.8%</td>
<td>38.6%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Scotland</td>
<td>29.7%</td>
<td>37.3%</td>
<td>46.6%</td>
<td>37.6%</td>
<td>44.9%</td>
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<tr>
<td>Wales</td>
<td>47.3%</td>
<td>60.9%</td>
<td>56.1%</td>
<td>54.7%</td>
<td>49.4%</td>
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<tr>
<td>UK and RoI (overall)</td>
<td>36.1%</td>
<td>40.3%</td>
<td>42.2%</td>
<td>45.7%</td>
<td>47.3%</td>
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