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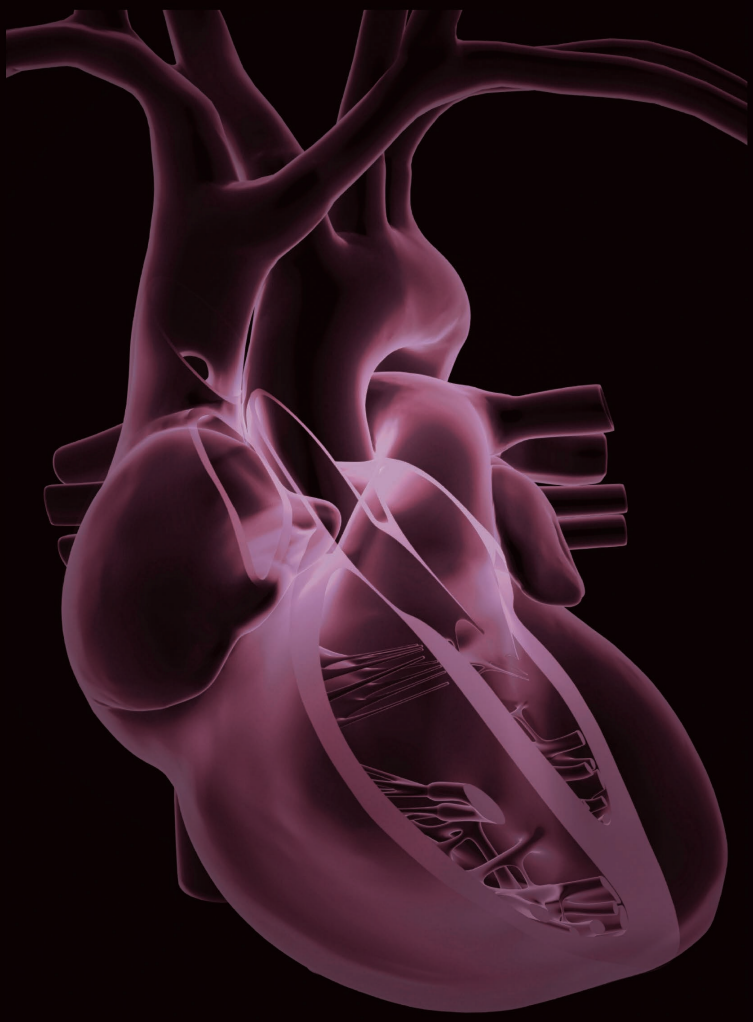

National Congenital Heart Disease Audit Report 2013-16

Annual Public Report 2013-16

NICOR (National Institute for Cardiovascular Outcomes Research) is a partnership of clinicians, IT experts, statisticians, academics and managers which manage 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 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 is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The National Audit of Congenital Heart Disease programme is funded by NHS England, the Welsh Government and, with some individual audits, also funded by the Health Department of the Scottish Government, DHSSPS Northern Ireland and the Channel Islands. **www.hqip.org.uk**

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Findings are based on validated mortality data

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Following a Europe-wide tender process, Bart's Health NHS Trust (Bart's Health) has been awarded the contract for NICOR to continue to manage the National Cardiac Audit Programme from 1st July 2017 to 30th June 2022. This includes the National Congenital Heart Disease Audit. Therefore on 1st July 2017, NICOR transferred from University College London to Bart's Health.

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Contents

A glossary of terms relevant to congenital heart malformations and their treatment can be found on the NCHDA website: https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/WGlossary?Openview&start=1&count=500

The terms units, centres or hospitals have been used interchangeably throughout the report.

1. Executive Summary

1.1 Who is the report for?

This report summarises all paediatric and congenital heart surgery, electrophysiology and transcatheter procedures undertaken in the UK. The report is aimed at clinicians, healthcare professionals, local audit teams, patients and the public and specialist commissioners.

What is congenital heart disease?

Congenital heart disease refers to any malformation or disease of the heart present from birth. It includes structural defects, congenital arrhythmias, and a minority of cardiomyopathies. Acquired heart disease develops after birth and examples of heart disease developed in childhood include inflammatory heart disease such as rheumatic heart disease, Kawasaki Disease and most cardiomyopathies. Where patients under 16 years of age with acquired heart disease undergo interventions they are included in the NCHDA.

At least 8 in every 1,000 babies are born with a heart or circulatory condition and currently in around a quarter of babies with any form of congenital heart disease, the heart defect is detected by antenatal ultrasound scans. The proportion of babies with more complex lesions (such as hypoplastic left heart syndrome) that are detected antenatally is much higher, close to 80%, as such severe defects are easier to be seen by the obstetric sonographer.

Congenital heart disease services

Congenital heart disease services are a relatively small speciality accounting for just over 1% of NHS specialised commissioning budget[1]. Services are concentrated in a small number of centres to ensure that there is a sufficient number of procedures undertaken to develop and retain skills, experience, and organisational processes. There is a need for them to be in close proximity to other specialist tertiary services. The services include the care of children with acquired heart disease. There are equivalent services in Scotland, Northern Ireland and the Republic of Ireland.

The National Congenital Heart Disease Audit

The National Congenital Heart Disease Audit (NCHDA) collects data from all centres undertaking paediatric and congenital cardiac surgery and interventional procedures, including electrophysiology, in the United Kingdom and Republic of Ireland (RoI). The audit focuses on monitoring activity levels and outcomes following cardiovascular procedures, as well as the success of antenatal diagnostic screening.

The audit aims to improve the quality of specialist congenital cardiovascular care by providing reliable, risk adjusted and independently validated data (for larger centres), including individual procedural counts, access to fetal cardiology screening and patient outcomes with respect to mortality. In future years, data on post-procedural complications will be included. Since 2007, the audit has published detailed results on the NCHDA website (https://nicor4.nicor.org.uk). The following report supplements the detailed results published on the website and summarises the key findings.

Who uses NCHDA data?

National Congenital Heart Disease Audit data are used to support a range of initiatives aimed at quality assurance and service improvement including the congenital heart service reviews undertaken by NHS England and by Specialist Commissioners. Examples are:

- Specialist congenital heart disease paediatric centres use NCHDA derived data to monitor the 30-day mortality and reoperation outcomes of patients with respect to their overall surgical performance using the Partial Risk Adjustment in Surgery version 2 (PRAiS2) risk adjustment software on a monthly basis.
- Specialist commissioners monitor patterns of activity and the quality of care using NCHDA derived metrics within the Specialised Services Quality Dashboards (SSQD) for paediatric and adult congenital heart disease[1], such as the use of PRAiS2 software by centres and the Data Quality Index calculated after validation site visits to individual centres. SSQDs are designed to provide assurance on the quality of care by collecting information about outcomes from healthcare providers. They are a key tool in monitoring the quality of services, enabling comparison between service providers and supporting improvements over time in the outcomes of services commissioned by NHS England.
- The NCHDA has supported the NHS England (NHSE) Congenital Heart Disease Service Review and provided information on activity as well as specialist advice on coding and reliability of Hospital Episode Statistics (HES) data across the NHS as a whole for congenital heart services in children and adults. NICOR has also undertaken an exploration of potential factors associated with suboptimal outcomes, such as ethnicity and distance from the specialist centre, as requested by NHSE, as well as a review of the potential use of 90 day post-procedural outcomes. The latter report will be available on the NICOR website in due course.
- The Care Quality Commission (CQC) and Healthcare Quality Improvement Partnership (HQIP) are developing information dashboards for use in CQC inspections. These are likely to be based on existing quality measures such as the Data Quality Index and 30-day post-procedural outcomes.

1. NHSE Specialised services quality dashboards: https://www.england.nhs.uk/commissioning/spec-services/npc-crg/spec-dashboards/
2. https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf

1.2 Methodology

Data collected by NCHDA

The NCHDA collects data prospectively on all paediatric and congenital heart surgery, electrophysiology and transcatheter procedures. The NCHDA does not currently publish data on the rarest procedures due to the very small numbers involved. This is in line with the Office for National Statistics (ONS) Confidentiality Guidance for publishing health statistics.[3] The 2013-16 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, meaning that 100% of relevant activity is encompassed by the analysis. Minor procedures which usually occur during the admission for a more major procedure, and non-cardiovascular procedures are not consistently collected or monitored (see Appendix 5).

The deadline for submitting 2015-16 data was May 15th 2016 and the data extraction date was 27th March 2017. This report covers 33,754 procedures undertaken during the three years between April 1st 2013 and March 31st 2016 (including 1,631 diagnostic catheter procedures for 2015-16).

Validation

The data have undergone a rigorous validation process comprising site visits by a clinical data auditor and volunteer clinician to all paediatric sites and the higher volume linked adult sites. The data are additionally verified by each submitting hospital as being accurate. The final validation visit for the 2015/16 data was 23rd November 2016.

Participation

The findings are based on individual patient data submitted by 14 combined paediatric and adult centres and 20 centres who only undertake procedures in adults with congenital heart disease, noting that Belfast ceased paediatric activity in December 2015. This covers all paediatric and adult congenital heart disease procedures in the NHS and private centres, except 10 non-submitting small volume adult centres, as well as collecting data on children having procedures for acquired heart disease, undertaken at centres in the UK and Republic of Ireland.

Analyses and risk adjustment

Due to the relatively small number of cases involved with a large number of different procedures, the audit provides composite 3-year outcome analyses, so as to minimise the risk of identifying individuals. This is in line with the Office for National Statistics (ONS) Confidentiality Guidance for publishing health statistics.[3]

Risk adjustment is a crucial part of reporting the results of procedures on children and adults born with congenital heart malformations and the audit uses appropriate methodology so as to compare data on a like for like basis. Congenital heart diseases vary considerably in complexity necessitating a great range of different operations to be offered, and children undergoing heart surgery may also have other non-cardiac conditions that make them more fragile. Hence operative risk may vary considerably, and in order to take differences in case complexity into account NCHDA reports post-operative outcomes in two different ways.

1. The audit reports the overall activities by the type of procedure and post-procedural 30-day survival as an outcome after 72 different surgical, transcatheter and electrophysiological interventional procedures, stratifying 30-day mortality risk according to the type of procedure undertaken. These are detailed on the NCHDA website and in Appendix 1a and 1b.[4]
2. The audit reports grouped programme-based outcomes for all paediatric cardiac surgery procedures inclusive of adjustment for case complexity based on the Partial Risk Adjustment in Surgery (PRAiS2) model.[5] PRAiS2 incorporates information on the specific procedure, age, weight, congenital heart diagnoses, and comorbid conditions that may be present. The software was updated in July 2016, such that PRAiS2 is the most up-to-date model, reflecting recent national outcomes (2009-15) and a more sophisticated approach to dealing with the operative risk linked to comorbidity.[6]

Identification and management of potential outliers

The NCHDA follows the Department of Health Outlier Policy,[7] 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.

Drawing on this policy, the audit uses two statistical control limits for its analyses (note, these percentages are not related to actual survival figures): an alert limit (97.5%) and an alarm limit (99.9%). If a unit's risk adjusted outcomes are better than both limits then its performance is not statistically different from the national average.

3. Review of the Dissemination of Health Statistics: Confidentiality Guidance (2006). https://www.ons.gov.uk/methodology/methodologytopicsandstatisticalconcepts/disclosurecontrol/healthstatistics
4. https://nicor4.nicor.org.uk/chd/an_paeds.nsf/vwContent/home?Opendocument
5. http://www.annalsthoracicsurgery.org/article/S0003-4975(16)31828-8/pdf
6. http://www.nets.nihr.ac.uk/projects/hsdr/141913
7. https://www.gov.uk/government/publications/detection-and-management-of-outliers-guidance-prepared-by-national-clinical-audit-advisory-group

Centres that fall outside the expected range are sometimes referred to as 'outliers'. NICOR is required to notify NHS England of any outlier hospitals within England and Wales. The hospital in question is contacted by NICOR and the relevant professional societies informed. Hospitals are asked to summarise information about the cases involved, local clinical practice and if relevant, lessons learned. Responses from hospitals are then reviewed by members of the NCHDA Steering Committee and the President of the British Congenital Cardiac Association (BCCA) and The Society for Cardiothoracic Surgery (SCTS).[8]

1.3 Key Findings: Patient Outcomes

- Overall programme-based survival at 30-days following paediatric heart surgery was within the appropriate range for all specialist childrens' heart units (97.5% and 99.9% prediction limits).
- Overall survival at 30 days was analysed for 72 major surgical, transcatheter cardiovascular and electrophysiological interventions undertaken to treat congenital heart disease at any age. In all hospitals 30-day survival was better than the alarm limit (99.5%) for all procedures and all but two hospitals were better than the alert limit (97.5%).
- Results show that two units had a potential outlier status: Our Lady's Children's Hospital in Dublin was a new potential outlier for one transcatheter procedure (balloon dilation of recoarctation in children); and Liverpool Heart and Chest Hospital for adult atrial septal defect closure for the second year running with a single additional death in fiscal year 2015-16.
- The response from Dublin was reviewed by members of the NCHDA Steering Committee and the Presidents of the BCCA and SCTS. The quality of local services was assured with no ongoing concerns for patients and their families. The response from Liverpool similar to the previous single death in fiscal year 2014-15, in that there were major comorbidities which contributed to the outcome for this patient. Responses from both hospitals will be provided on the NICOR website.[9]
- There has been ongoing improvement in antenatal diagnosis of congenital heart disease over the past 7 years, although still below 60%. Between 2010-16, just over 50% (n = 10,954) of infants who required a procedure to treat a congenital heart malformation in the first year of life, were diagnosed through antenatal screening, compared to less than a quarter of cases in 2004/5. Although there has been progress over time, there is still room for further improvement. This remains as good as, or better than, the most recently reported annual detection rate in North America, albeit from 2006-12.[10]

Activity

- Monitoring patterns of activity by centre is key to ensuring procedures are only undertaken by centres that offer specialist expertise. In 2015-16, UK and RoI centres submitted data on 10,887 procedures where 7,695 were paediatric cases and 3,192 were adult cases. A breakdown by age group is shown in Appendix 1a and additionally by age group is available on the NCHDA website.[11] A more detailed breakdown by centre is shown in Appendix 1c (surgical activities).

1.4 Summary of recommendations

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

In order to ensure Data Quality is of the highest standard for quality assurance and quality improvement initiatives, we recommend that you:

1. Ensure that your Specialist Surgical Centre has a minimum of 1 Whole Time Equivalent (WTE) dedicated paediatric cardiac surgery/cardiology Database Manager (DBM) at Band 7 Agenda for Change, with at least 1 WTE assistant (at least Band 6), 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).[12]
2. Ensure there are sufficient resources allocated to, and sufficient processes put in place, to fully support national clinical audit activity, including local Information Technology support and software that fully accommodates the NCHDA dataset for timely submission of data and verification of data quality. Each DBM should have their own user ID and password to access the NCHDA database and make timely submissions.
3. Ensure all patients undergoing CHD procedures have a preceding congenital cardiology Multidisciplinary Team (MDT) meeting, including all adult patients, in accordance with the congenital cardiology service specification published as part of the NHS England New CHD Review (2015), thereby minimising occasional practice for adult CHD procedures.[12]
4. 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 better data completeness and data quality. Each clinical

8. https://nicor5.nicor.org.uk/__80257061003D4478.nsf/vwContent/home?OpenDocument
9. https://nicor4.nicor.org.uk/chd/an_paeds.nsf/vwContent/Analysis%20Documents?Open
10. From 2012-15 report: 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.
11. https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/WSummaryYears?openview&RestrictToCategory=2013&start=1&count=500
12. https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf

audit should have an identified Clinical Audit Lead assigned to support this activity. The clinical lead should have protected time to be involved with the regular validation of data to be submitted, as well as PRAiS2 analysis.

5. Ensure all operators regularly review their data submitted to the NCHDA to improve timeliness and accuracy. This should be on at least a quarterly basis but monthly for large centres. Trusts should engage with the NCHDA annual validation process and site visits, considering and implementing recommendations therein. Relevant clinicians (consultants and trainees) should engage with robust data quality assurance and completeness procedures. All centres undertaking congenital cardiology procedures should submit data to the NCHDA, including adult patients with CHD.

II. Chief Executives, Medical Directors and Clinical Leads at Centres providing antenatal screening for congenital heart malformations

We recommend that you:

1. Target quality initiatives such as staff training and optimisation of sonographic equipment, to enable improvements in antenatal ultrasound scanning detection rates of congenital cardiac conditions. This is in accordance with NHS Fetal Anomaly Screening Programme guidance and recommendations,[13] and the Fetal Cardiology Standards of the British Congenital Cardiac Association.[14]

2. Ensure that feedback mechanisms and links are in place between the paediatric, cardiology and antenatal ultrasound scanning departments to enable learning relating to cases of congenital heart disease where antenatal sonography failed to detect the defect. This will be facilitated by the NHCDA fetal cardiac screening results being made fully available to the UK National Fetal Cardiology Group, so that its members can target individual centres whose performance needs to improve.

III. Congenital Cardiology Clinical Audit Teams

We recommend that you:

1. 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.

2. 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. The clinical lead should be involved (hands on) with the regular validation of data to be submitted, as well as PRAiS2 analysis. This needs to be protected time.

3. 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).

4. Ensure that those centres undertaking paediatric congenital cardiology operations present and review their internal VLAD plots generated by the PRAiS2 analyses at monthly congenital cardiology meetings. It is important to review the data at MDT mortality & morbidity meetings, documenting discussions and resulting action points. These are discussed with specialised commissioners as part of the quarterly quality meetings, where appropriate.

5. 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.

IV. Patients and Public

1. This report, along with the NCHDA website, allows you to review the activity of local centres as well as outcomes, such as survival following major procedures. We also report a comparison of risk adjusted mortality for the whole programme of surgical activity in children for all paediatric centres. We identify alerts and alarms, publishing subsequent responses from specialist centres.

2. Families and patients, along with other interested parties, are strongly encouraged to view the recently launched 'Understanding Children's Heart Surgery Outcomes' website: http://childrensheartsurgery.info/

   The website gives a comprehensive and accessible explanation of the way NCHDA has analysed whole centre outcomes using PRAiS software and the underlying survival statistics. It also provides an understanding of why risk adjusted outcomes are needed for procedures involving congenital heart malformations. In essence, knowing and understanding the risk factors for each child allows us to predict the percentage of children within a group that will survive, even though we cannot predict exactly whether individual children will survive.

   The NCHDA uses a statistical formula to combine data on these risk factors for all the children a hospital has treated over the previous three years to give a predicted range for the overall proportion of survivors for that specific hospital and time period. The formula is also used to calculate an extended predicted range for survival for each hospital. The audit body then compares the survival rate achieved by a hospital with its predicted and extended predicted range.

13. https://www.gov.uk/guidance/fetal-anomaly-screening-programme-overview
14. http://www.bcs.com/documents/Fetal_Cardiology_Standards_Final_Version_March_2010.pdf

2. Introduction

2.1 Congenital Heart Disease

Congenital heart disease refers to any defect malformation or disease of the heart present from birth. It includes structural defects, congenital arrhythmias, and a minority of cardiomyopathies. Acquired heart disease develops after birth. Examples of heart disease that may develop in childhood include inflammatory heart disease such as rheumatic heart disease, Kawasaki Disease and most cardiomyopathies.

At least 8 in every 1,000 babies are born with a heart or circulatory condition. The diagnosis and treatment of complex heart malformations has improved over the past few decades.[15] As a result, almost all children born with complex heart defects survive to adulthood.[16]

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, and all those for children, are undertaken at dedicated congenital heart disease centres. Some adults with relatively minor malformations receive care at other centres, but there is currently a drive by NHS England to ensure that all CHD procedures are undertaken by specialist centres or at a minimum undergo an adult CHD focussed Joint Cardiosurgical Conference MDT meeting review to ensure management is optimal for that individual.

Antenatal diagnosis of a congenital heart malformation

A goal of congenital heart disease services is to diagnose heart disease as early as possible and the ideal is before birth, referred to as antenatal diagnosis. Currently in around a quarter of babies with any form of congenital heart disease, the heart defect is detected by antenatal ultrasound scans. However, although the proportion of infants detected with a heart anomaly requiring an intervention is only just over 50% in the latest NCHDA data, for babies with more complex lesions (such as hypoplastic left heart syndrome) antenatal detection is known to be much higher, at least 80%, as such severe defects are easier to be seen by the obstetric sonographer.[17] 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 recognise and promptly treat major congenital heart disease is associated with increased morbidity and mortality rates, and is recognised as an important quality-of-care issue.[18]

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 catheterisation procedures. The audit currently provides the following information:

- Overall programme level survival at 30-days after paediatric heart surgery for all paediatric specialist centres, as an aggregate of all procedures undertaken (PRAiS2 analysis).
- Overall survival at 30-days for each of the 72 surgical, transcatheter cardiovascular interventions and electrophysiology procedures, both in children and adults.
- Rates of overall antenatal diagnosis of congenital heart disease by region and country. Currently this is with respect only to those who survive pregnancy and then undergo a procedure in infancy.

2.3 Supporting Quality Assurance and Improvement

The NCHDA has been publicly reporting outcomes for surgical and interventional procedures for over a decade and traditionally has aimed to improve the quality of specialist services by:

- **Monitoring:** Activity and outcomes are monitored 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 NHS Digital through the Office of National Statistics (ONS) providing reliable information about the immediate and short term outcomes for children.[19]
- **Data sharing:** The data are used to support a range of initiatives aimed at quality assurance and service improvement including the congenital cardiology reviews undertaken by NHSE and for specialist commissioners. Examples of how data are 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 antenatal fetal cardiac anomaly screening detection rates:** Reports on the success of antenatal diagnosis of severe congenital heart disease (requiring

15. 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
16. https://www.bhf.org.uk/publications/statistics/children-and-young-people-statistics-2013
17. Marek J, Tomek V, Skovránek J, et al. Prenatal ultrasound screening of congenital heart disease in an unselected national population: a 21-year experience. Heart 2011 97: 124-130. doi: 10.1136/hrt.2010.206623
18. 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
19. Note: Life status at one year is only published on the public website and not in this document, due to the time difference in reporting. One year life status for patients admitted between April 1st 2015 and March 31st 2016 will be published in November 2017 along with unvalidated 2016/17 data, as it is necessary to wait 12 months after March 31st 2016, as well as having confirmation of life status from ONS.

a procedure in infancy) at a regional level can stimulate quality improvement efforts, such as thorough training of sonographers and optimising sonographic equipment.

Whilst these are key areas, the current report includes a variety of broader quality assurance and potential areas for quality improvement initiatives.

- **Dissemination/Reporting:** The results of PRAiS2 congenital cardiology risk adjusted analyses are explained to all stakeholders, particularly patients and families, on the website http://childrensheartsurgery.info/, which was launched in June 2016 to much acclaim from the media, journals and patient-family support organisations.[20]
- **Engaging clinicians to use the results for improvement and enhanced clinical effectiveness:** All 13 current paediatric congenital heart tertiary (Level 1) centres use bespoke PRAiS2 software linked to NCHDA to monitor in house 30-day mortality and reintervention outcomes on a monthly basis. The use of this software and its monitoring is mandated as a standard in the NHSE New CHD Review[21] and is a metric in the Congenital Heart Services Specialist Quality Dashboard (SSQD). Deviation from expected outcomes is then expected to be investigated by the Centre and mitigating circumstances understood and/or quality improvement measures instigated.

The published outcomes of antenatal screening success for infants requiring an intervention show which regions of the UK perform best and least well. This allows those fetal screening centres performing less well to look at the possible reasons behind this, which is likely to be related to the quality of sonographic equipment and issues around maternity sonographer training.

- **Improvement in the quality of care and patient outcomes:** The outcome measure that is the main focus of this report is 30-day survival, and in this regard there is consistent evidence for improvement once case mix complexity has been taken into consideration. After its first use in 2012, the benchmarking risk model PRAiS had to be recalibrated because of improvement in 30-day outcomes. This was repeated again such that the benchmarking risk adjustment model PRAiS2, which was released in 2016, contained a further recalibration reflecting continued improvement after 2012. The latest Variable Life Adjusted Display (VLAD) chart shown in this report suggests that risk adjusted 30-day outcomes have continued to improve from 2015 to 2016. Whilst this is very reassuring news for stakeholders, it must underpin a commitment to move beyond 30-day survival rates and explore methods to assess longer term survival, the incidence of post-procedural complications, and other measures of functional outcome in survivors.
- **Best practice:** Overall risk adjusted survival at 30 days was much higher than the predicted level at one centre: Great Ormond Street Hospital in London for the second three year cycle in a row. This is indicative of good performance and should present an opportunity for sharing best practice across specialist centres.

  All of the specialist congenital heart disease centres submit data to the audit. However, although this is a mandatory audit, there are a small number of hospitals (approximately 10%) that undertake relatively minor procedures for adults with congenital heart disease, who do not submit data to the NCHDA. This information is gleaned from the BCIS (British Cardiovascular Intervention Society) annual survey.[22] This includes atrial septal defect and patent foramen ovale closure procedures, percutaneous pulmonary balloon valve dilation, and coarctation of the aorta stent or balloon dilation. It is encouraging that Papworth has now started submitting to NCHDA for the first time. Other centres that do not submit data are Wythenshawe, Edinburgh Royal Infirmary, and a number of private hospitals treating adult patients.

20. Pagel C, Jesper E, Thomas J, Blackshaw E, Rakow T, Pearson M, Spiegelhalter D. Understanding Children's Heart Surgery Data: A Cross-Disciplinary Approach to Codevelop a Website. Ann Thorac Surg. 2017 Mar 15. pii: S0003-4975(16)31821-5

21. https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf

22. https://www.bcis.org.uk/wp-content/uploads/2017/01/BCIS-audit-2014.pdf

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 Quality Dashboard related submissions. 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 the most recent 3 year mortality scores using their in house PRAiS data.
NHS England Service Review	The NCHDA has supported the NHS England Service Review by providing the following analyses: • 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. • Activity split of transcatheter interventions and electrophysiological procedures, as published in the current report. • 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.
Care Quality Commission	From 2017, NCHDA audit data will be used to provide information for Care Quality Commission inspections.
Outcomes based research	NCHDA data are actively used for clinical research aimed at reporting outcomes locally and nationally. A full list of research projects is available on the NICOR website.

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 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 Congenital Heart Disease Audit (NCHDA) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

HQIP commissions and funds the NCHDA on behalf of NHS England and the Welsh Government. 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 NCHDA Steering Committee. This includes major stakeholders in the audit, including congenital cardiac surgeons and cardiologists, the professional societies, a congenital cardiology database manager and a patient and public group representative.

3. Methodology

3.1 Participation

The audit collects individual patient data from all centres undertaking major congenital heart disease procedures in England, Scotland, Wales, Northern Ireland and the Republic of Ireland. There are 14 combined paediatric and adult centres and 20 centres which only undertake procedures in adults with congenital heart disease. Belfast ceased undertaking procedures in children in December 2015 and so their data are not included in the 3-year PRAiS analysis. This covers all NHS and private paediatric and congenital heart disease procedures, except for those undertaken in 10 non-submitting small volume adult centres. Information related to activity is broken down into four groups:

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

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. The audit does not include data with respect to adults undergoing procedures for acquired heart disease, such as degenerative vascular disease giving rise to aortic aneurysm, dissection or the need for coronary artery bypass surgery in adults.

The NCHDA annual audit period is from April 1st to March 31st, the deadline for submitting 2015-16 data was May 15th 2016 and the data extraction date was 27 March 2017. The analyses are based on 33,754 surgical and interventional procedures undertaken during the three years between April 1st 2013 and March 31st 2016. Participating centres with their 3-year major activity are listed in Table 2 (Diagnostic catheter excluded).

Table 2: Centres undertaking major congenital cardiac procedures 2013 – 2016

Hospital Name	Hospital Code	Child	Adult	Total
Centres undertaking paediatric and adult congenital heart disease procedures				
Belfast, Royal Victoria Hospital	RVB	206	279	485
Birmingham Children's Hospital	BCH	2629	99	2728
Bristol Royal Hospital For Children	BRC	1542	893	2435
Dublin, Our Lady's Children's Hospital	OLS	2029	51	2080
Glasgow, Royal Hospital for Children	RHS	1252	36	1288
Leeds General Infirmary	LGI	1843	785	2628
Leicester, Glenfield Hospital	GRL	1184	448	1632
Liverpool, Alder Hey Hospital	ACH	1797	55	1852
London, Evelina London Children's Hospital	GUY	2050	695	2745
London, Great Ormond Street Hospital for Children	GOS	3116	117	3233
London, Harley Street Clinic	HSC	467	96	563
London, Royal Brompton Hospital	NHB	2049	1043	3092
Newcastle, Freeman Hospital	FRE	1334	444	1778
Southampton, Wessex Cardiothoracic Centre	SGH	1449	523	1972
Centres undertaking primarily adult congenital heart disease procedures in general These are ACHD hospitals that mainly carry out adult CHD procedures, but also carry out a very small number of paediatric cases				
Basildon, Essex Cardiothoracic Centre	BAS	0	9	9
Birmingham Queen Elizabeth Hospital	QEB	*	394	395
Blackpool Victoria Hospital	VIC	0	55	55
Brighton, Royal Sussex County Hospital	RSC	0	174	174
Bristol Spire Bristol Hospital	GHB	0	*	*
Cambridge, Papworth Hospital	PAP	0	208	208
Cardiff, University Hospital of Wales	UHW	0	67	67
Glasgow, Golden Jubilee National Hospital	GJH	5	447	452
Liverpool Heart and Chest Hospital	BHL	*	356	357
London, Barts Heart Centre†	SBH	0	214	214
London, Hammersmith Hospital	HAM	0	67	67
London, King's College Hospital	KCH	0	29	29
London, St George's Hospital	GEO	0	56	56

London, University College Hospital †	UCL	0	432	432
Manchester Royal Infirmary	MRI	*	541	542
Nottingham City Hospital	CHN	0	80	80
Oxford, John Radcliffe Hospital	RAD	*	253	257
Sheffield, Northern General Hospital	NGS	0	56	56
Stoke, University Hospital of North Staffordshire	STO	0	120	120
Wolverhampton Heart & Lung Centre	NCR	0	40	40

Note: Therapeutic procedures comprise surgical procedures (bypass, non-bypass, hybrid, lung transplant, Ventricular Assist Device (VAD) and primary Extracorporeal Membranous Oxygenation mechanical life support (ECMO) procedures), transcatheter interventions and electrophysiological procedures (including pacing and Implantable Cardioverter Defibrillator (ICD) procedures). Diagnostic catheter, minor and excluded non-cardiac procedures (Appendix 5) are not included.

†All CHD activity at University College Hospital, which was housed at The Heart Hospital, moved to the Barts Heart Centre in April 2015.
*Numbers lower than 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.	2013 -16	- Under 16 years	All surgical procedures (risk adjusted) All cardiovascular surgical procedures including hypoplastic left heart related hybrid procedures. This excludes lung transplant, VAD/primary ECMO support procedures and minor/non-cardiovascular procedures.
Specific procedures: outcome at 30 days after procedure	2013 -16	- Under 16 years - 16 years and over	Seventy-two surgical, and interventional-electrophysiological procedures for paediatric and congenital heart disease, excluding minor/non-cardiovascular procedures. VAD/primary ECMO support and lung transplant procedures are also reported for activity counts only. For full listing of these, see Appendix 1.

Note: VAD, Ventricular Assist Device; ECMO, Extracorporeal Membranous Oxygenation mechanical life support.

A full list and definition of specific surgical and transcatheter interventional procedures can be found on the NCHDA website at 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, as well as a glossary of related terminology.

3.3 Coding

The audit uses the European Paediatric Cardiac Code coding system (http://www.aepc.org/european-paediatric-cardiac-codi/), which is a subset of the International Paediatric and Congenital Cardiac Code (IPCCC; www.ipccc.net) used for all diagnoses, comorbidities, all procedures and complications. A full list of the codes is available via the NCHDA website at http://www.ucl.ac.uk/nicor/audits/congenital/datasets

3.4 Data Quality and Validation

The audit uses site visits and remote validation methods to ensure that data quality is of a high standard. Site visits are undertaken by the NICOR clinical data auditor and a volunteer clinician to ensure full case ascertainment and to verify the accuracy of the data submitted to the audit. These data are also signed off and approved by each local hospital as being accurate and the same as the data submitted to the NCHDA database; a process known as reverse validation.

All paediatric centres and larger adult centres have site visits, whilst currently this is only offered to the much larger adult centres. There are three stages to the validation process. The first involves a review of 20 randomly selected hospital records of congenital patients. Previously submitted data for the same 20 patients are cross-checked against their hospital notes. After the checking process the hospital 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 (i.e. demographics, pre-procedure, procedure and outcome), which ideally is expected to be greater than 90%.

The second stage assesses the theatre and catheter laboratory logbooks. These are examined to ensure all appropriate cases have been submitted, with correct procedure and diagnosis coding, adding and deleting cases as appropriate. The third stage examines the records of all deceased cases in the audit year to ensure the accuracy of diagnoses, procedure(s) undertaken and any additional comorbid factors, again

comparing against the data submitted.

Remote validation involves a series of checks that include sense checking of the data before the first round of analysis and confirmation of the number of specific procedures and deaths.

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 2015/16. Analysis is restricted to include all patients under 12 months of age who undergo surgical and/or transcatheter therapeutic procedures. The analysis excludes closure procedures for persistent patent arterial duct, patent foramen ovale or atrial septal defect, as these conditions are not diagnosed antenatally.

3.6 Statistical methodology

3.6.1 Small numbers

Due to the great number of possible congenital heart disease diagnoses with a similarly large number of different therapeutic procedures that are undertaken for such patients, there is a relatively small number of patients having the same operation. This means that there is a small risk of identifying individuals from publishing specific procedure outcomes. The audit therefore provides a composite 3-year outcome analysis to minimise this risk, which is in line with the Office for National Statistics (ONS) Confidentiality Guidance for publishing health statistics.[23]

3.6.2 Risk adjustment and risk stratification

This is a process used to account for the impact of individual risk factors. These include the type of procedure itself with its inherent risks, the patient's age, any coexistent conditions such as syndromes and extracardiac malformations, severity of illness and acquired co-existent heart problems. These factors can put some patients at greater risk of adverse outcomes than others. Risk adjustment – or risk stratification – is a crucial part of reporting the results of procedures on children and adults born with congenital heart malformations. Two methods are used:

1. 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 audit reports the comparative outcomes after 72 individual surgical, transcatheter cardiovascular and electrophysiological interventional procedures, stratifying 30-day survival risk according to the type of procedure undertaken. The type of procedure undertaken at each hospital varies and a full list of procedures including a glossary describing each procedure is available on the NCHDA website.
2. The audit uses specifically designed and validated software to report risk adjusted centre whole programme outcomes, known as Partial Risk Adjustment in Surgery (PRAiS). PRAiS encompasses all cardiovascular surgical procedures, whilst excluding minor and non-cardiovascular operations (listed in Appendix 5), and not including transcatheter interventions. This software estimates the risk of death within 30 days of a primary surgical procedure in a paediatric patient. This is based on the specific procedure, the patient's age, and weight, as well as the patient's recorded diagnoses, and important comorbid conditions that may be present. 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 17, and on the PRAiS model via the UCL Clinical Operational Research Unit.[24]

   The PRAiS software was updated to version 3.0.2 in July 2016 (PRAiS2). PRAiS2 is based on the most up-to-date national audit dataset and incorporates new independent risk factors of congenital comorbidity, acquired comorbidity, increased severity of illness and additional cardiac risk factors. The PRAiS2 model performed extremely well during validation and the detailed explanation and description of all its features will be available on the NICOR website during 2017. In addition, PRAiS2 was generated using more recent national outcomes (2009-15) than the previous PRAiS model, effectively raising the bar for outcomes as 30-day mortality has progressively fallen year on year in the UK and RoI for children undergoing congenital heart disease related surgery.[25] 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.

3.6.3 Evaluation of outcome

The main outcome measure reported by NCHDA for procedures that have been undertaken is 30-day survival. This outcome is ascertained based on notifications from participating units that a patient has died and further by independent verification of up-to-date life status for patients

23. Disclosure control guidance for birth and death statistics 2014. https://www.ons.gov.uk/methodology/methodologytopicsandstatisticalconcepts/disclosurecontrol/guidanceforbirthanddeathsstatistics
24. http://www.ucl.ac.uk/operational-research/domains/congenital_heart_disease/prais
25. http://www.nets.nihr.ac.uk/projects/hsdr/141913

resident in England and Wales who have an NHS number by the Office of National Statistics.

For the PRAiS analyses, the outcome is based on the patient's vital status on completion of a 30-day episode of surgical management. Re operations that occur within this 30-day episode period are not included in the PRAiS analyses in order to avoid double counting of deaths.

For the analyses of outcome after individual specific procedures, 30-day survivals are aggregated in a 3 year period for a given procedure. If a patient has the exact same procedure more than once within 30 days of the first procedure, only the first one is included.

For outcomes based on aggregations across specific procedure types, i.e. where more than one type of procedure is added together to give a total procedure number and a total number of deaths such as is shown in Appendix 1b, these totals are based on procedures rather than patients and as such there is the potential for both a survivor and a death to be counted more than once.

3.7 Control limits

The audit uses two control limits: an alert limit (97.5%) and an alarm limit (99.9%) as per the Department of Health Guidance on detecting outliers. If a unit's results are above both limits then their performance is not statistically different from the average survival rates of all the centres submitting data.

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 the same set of control limits is used.

Note: As there are only 13 centres in the paediatric analysis this means that there is a 25.5% risk of at least one centre being beyond the 97.5% limit and a 1.35% chance of being beyond the 99.9% limit by random chance (i.e. a false positive or negative outlier).

4. Findings

4.1 Number of procedures

In 2015-16, thirty two centres submitted data on 10,887 procedures, 7,695 were paediatric patients and 3,192 were adult patients (Table 4). The full analysis is based on data submitted between 1st April 2013 and 31st March 2016 (Table 5), during which time there were 32,123 congenital heart disease related surgical and interventional procedures undertaken, and an additional 1,631 diagnostic catheter procedures (2015-16 only).[26]

There has been a year on year increase in the number of procedures undertaken and activity levels have increased by almost 40% since 2003 and they now appear to have largely stabilised over the last few years at just over 10,000 cases per year (Table 6), excluding diagnostic catheterisation rates.

Antenatal diagnosis analysis is based on 10,954 procedures undertaken between 1st April 2013 and 31st March 2016 on patients who then had a surgical or interventional procedure in their first year of life.

Table 4. Number and type of major procedures submitted by provider 2015-16

Provider	Paediatric			ACHD			All Ages		
	Surgical	Catheter - EP	Total	Surgical	Catheter - EP	Total	Surgical	Catheter - EP	Total
England	3925	2527	6452	929	1937	2866	4854	4464	9318
Northern Ireland	5	5	10	41	60	101	46	65	111
Republic of Ireland	336	392	728	7	6	13	343	398	741
Scotland	231	171	402	94	72	166	325	243	568
Wales	0	0	0	*	18	20	*	18	20
Private	91	12	103	22	*	26	113	16	129

Note: Surgical procedures include bypass, non-bypass, hybrid, lung transplant, Ventricular Assist Device (VAD) and primary Extracorporeal Membranous Oxygenation mechanical life support (ECMO) procedures. Catheter-Electrophysiology procedures (Catheter-EP) include transcatheter interventions and electrophysiological procedures (including pacing and Implantable Cardioverter Defibrillator (ICD) procedures), whilst excluding diagnostic catheter procedures.

*Numbers lower than 5

Table 5. Number and type of major procedures submitted by provider 2013-16

Provider	Paediatric			ACHD			All Ages		
	Surgical	Catheter - EP	Total	Surgical	Catheter - EP	Total	Surgical	Catheter - EP	Total
England	11838	7162	19000	2891	5295	8186	14729	12457	27186
Northern Ireland	80	126	206	92	187	279	172	313	485
Republic of Ireland	1040	989	2029	11	40	51	1051	1029	2080
Scotland	767	490	1257	330	153	483	1097	643	1740
Wales	0	0	0	17	50	67	17	50	67
Private	351	116	467	64	34	98	415	150	565

Note: Surgical procedures include bypass, non-bypass, hybrid, lung transplant, Ventricular Assist Device (VAD) and primary Extracorporeal Membranous Oxygenation mechanical life support (ECMO) procedures. Catheter-Electrophysiology procedures (Catheter-EP) include transcatheter interventions and electrophysiological procedures (including pacing and Implantable Cardioverter Defibrillator (ICD) procedures), whilst excluding diagnostic catheter procedures.

*Numbers lower than 5

26. Note: for simplicity Hybrid procedures are included in the surgical procedure count in Table 4 and Table 5.

Table 6. Total number of cases submitted to the NCHDA by financial year.

Year	Surgical	Hybrid	Catheter - Electrophysiology			Diagnostic Catheter	Total
			Interventional	EP/Pacing	ICD		
2003-04	4497	0	2928			—	7425
2004-05	4346	0	3032			—	7378
2005-06	4638	*	3490			—	8131
2006-07	4794	7	3769			—	8570
2007-08	4771	10	3616			—	8397
2008-09	4949	14	3910			—	8873
2009-10	5262	6	3963			—	9231
2010-11	5852	6	4310			—	10168
2011-12	5710	29	4498			—	10237
2012-13	5849	16	4372			—	10237
2013-14	6024	50	3720	944	109	—	10847
2014-15	5662	62	3511	1037	117	—	10389
2015-16	5630	53	3731	1347	126	1631	12518

Note: Isolated diagnostic catheter procedures were systematically collected from April 2015. Although they feature as part of many therapeutic procedures, in these circumstances they are not included as a separate procedure, or in the total numbers elsewhere in this table. The numbers here are purely for diagnostic catheters in isolation.

*Numbers lower than 5

4.2 Data Quality Indicators

The NCHDA standard for data quality is 90% accuracy. Nearly all centres had DQI scores of 90% and above (Appendix 3a and 3b). Above 95% is excellent (shown in bold in tables 3a & 3b). Overall the average DQI has improved year on year for paediatric centres, and although more erratic for adult (ACHD) centres, 2016-17 site visits looking at 2015-16 data have also shown further improvement.

All but one centre receiving an on-site validation visit in 2016 had an overall DQI score of over 90%. The exception was Queen Elizabeth Hospital, Birmingham with an overall DQI score of 75%. Centres not achieving the requisite standard of over 90% have consistently received detailed feedback including recommendations on how to improve data quality. Queen Elizabeth Hospital, Birmingham has confirmed that the staffing shortage has been addressed with protected time to monitor quality and accuracy of all ACHD data. These centre site visit reports are available on the NCHDA website.[27] As this is the third consecutive year the hospital has failed to meet the required standard, NICOR has notified the medical director and NHS England.

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

30-day survival was analysed in 72 major surgical, and transcatheter cardiovascular interventions undertaken to treat congenital heart disease at any age. This is a considerable increase from the previous 57 procedures reported in 2011-14 and 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 the following exceptions:

- Dublin – Our Lady's Children's Hospital – This was a new potential outlier for one transcatheter procedure (balloon dilation of recoarctation in children).
- Liverpool Heart and Chest Hospital – This was an outlier for adult surgical atrial septal defect closure for the second year running with a single additional death in fiscal year 2015-16.

In line with Department of Health (DoH) Outlier Policy, the hospitals were contacted by NICOR and the relevant professional societies were notified. The hospitals were asked to summarise information about the case(s), local clinical practice and if relevant, lessons learned. This year, the response from Dublin – Our Lady's Children's Hospital has been reviewed by members of the NCHDA Steering Committee, the President of BCCA and the CHD leads for the SCTS the quality of local services was assured. Liverpool Heart and Chest Hospital was a potential outlier for the second year running, with a single death in each year. Both patients

27. https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument

were complex with considerable additional non-related illnesses (comorbidities) and were therefore at higher risk for this usually straight forward procedure. Responses from both hospitals will be available on the NICOR website.

The results for all 72 procedures for children and adults are available on the NCHDA public website: Specific Procedures 2013-2016. https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument. A table of all procedures undertaken for congenital heart disease from 1st April 2013 to 31st March 2016 inclusive is available in Appendix 1. There are 72 distinct procedures reported, covering 85% of all procedures, along with a summation of the 15% of miscellaneous procedures reported with low individual procedure frequency. In addition there is a listing of activity related to lung transplants which is undertaken on bypass and by the same surgeons as the other procedures, as well as standalone cardiovascular mechanical support procedures (Ventricular Assist Device (VAD) implantation and removal, primary Extracorporeal Cardiovascular Membrane Oxygenation (ECMO) used as a bridging procedure (not as a rescue procedure after another CHD procedure).[28]

4.4 Surgical Procedures: 30-day risk adjusted survival rates (centre level whole program aggregated data) using PRAiS2 methodology and software – Paediatric cases only

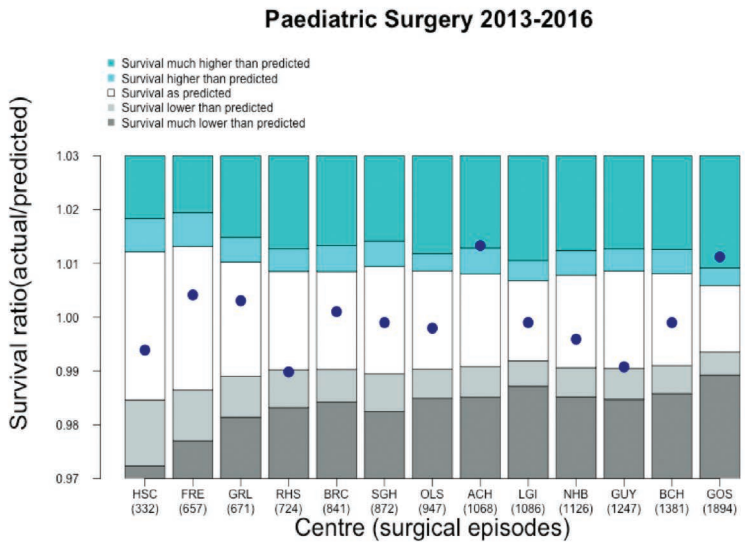
Paediatric cardiac surgical or interventional procedures are defined as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years. Figure 1 and Table 8 show the number of surgical episodes, 30-day survival rates and the actual versus predicted survival ratio for paediatric surgery only, using PRAiS methodology. All cardiovascular surgical procedures including hypoplastic left heart related hybrid procedures are included in the analysis. However, PRAiS2 2 excludes lung transplant, VAD/ECMO support procedures and minor/non-cardiovascular procedures.

The results show that in all hospitals 30-day survival was better than the alarm and alert limits (99.5% and 97.5%) for their aggregated outcomes encompassing all surgical procedures. It is also noteworthy that one centre had results with an overall risk adjusted survival at 30-days much higher than the predicted level for the second year running: Great Ormond Street Hospital in London. This is indicative of good performance and represents an opportunity for sharing more optimal practice across specialist centres.

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 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 of 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. For more detailed explanation, see http://childrensheartsurgery.info/

Fig 1. Actual vs Predicted Survival Rates for all 13 centres undertaking procedures in patients under 16 years of age 2013-2016 using PRAiS Risk Adjustment methodology.



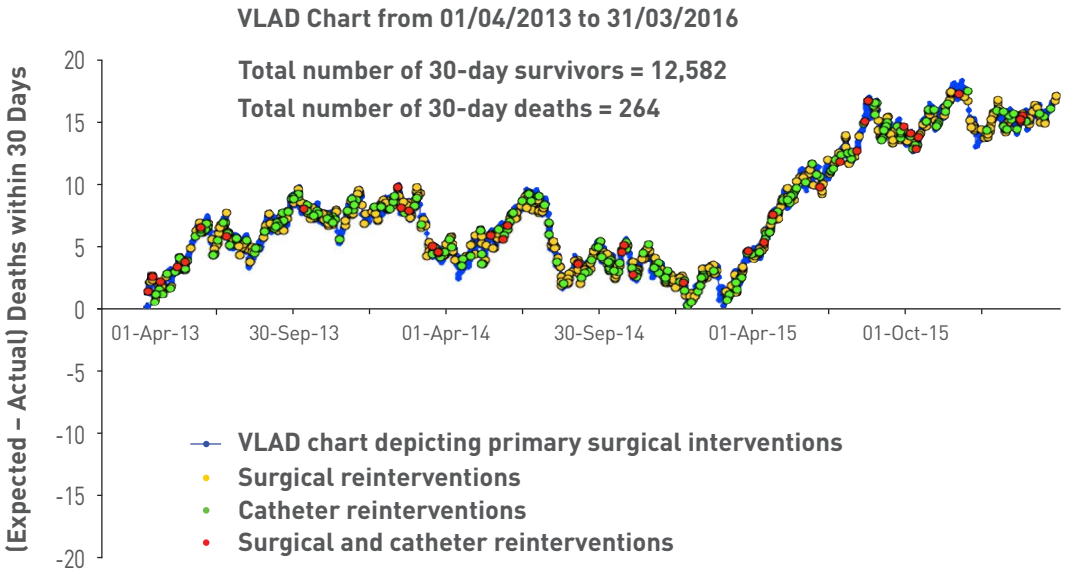
Note: Outcomes are adjusted for procedure, age, weight, diagnosis, comorbidities and procedures performed.

28. Note: 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 7. Actual and Predicted Survival Rates 2013-16, using PRAiS Risk Adjustment methodology, for all 13 units undertaking procedures in patients under 16 years of age.

Hospital	Unit	Surgical episodes	Actual survival	Predicted survival	Actual / Predicted survival	Survival summary
London, Harley Street Clinic	HSC	332	97.6%	98.20%	0.994	as predicted
Newcastle, Freeman Hospital	FRE	657	97.3%	96.90%	1.004	as predicted
Leicester, Glenfield Hospital	GRL	671	98.4%	98.10%	1.003	as predicted
Glasgow, Royal Hospital for Sick Children	RHS	724	97.2%	98.20%	0.990	as predicted
Bristol Royal Hospital For Children	BRC	841	98.2%	98.10%	1.001	as predicted
Southampton, Wessex Cardiothoracic Centre	SGH	872	97.6%	97.70%	0.999	as predicted
Dublin, Our Lady's Children's Hospital	OLS	947	97.9%	98.10%	0.998	as predicted
Liverpool, Alder Hey Hospital	ACH	1,068	99.2%	97.90%	1.013	higher than predicted
Leeds General Infirmary	LGI	1,086	98.4%	98.50%	0.999	as predicted
London, Royal Brompton Hospital	NHB	1,126	97.5%	97.90%	0.996	as predicted
London, Evelina Children's Hospital	GUY	1,247	96.5%	97.40%	0.990	as predicted
Birmingham Children's Hospital	BCH	1,381	97.3%	97.40%	0.999	as predicted
London, Great Ormond Street Hospital for Children	GOS	1,894	99.2%	98.10%	1.011	much higher than predicted

Fig 2. Variable Life Adjusted Display (VLAD) Chart for all 13 paediatric centres undertaking procedures in patients under 16 years of age, 2013-16.



The Y-axis shows predicted minus actual deaths at 30 days. A positive value therefore indicates improved survival. Trends in outcomes continue to improve in 2015-16 using the newly recalibrated PRAiS2 software.

Note: This VLAD chart uses different (PRAiS2) risk adjustment to the 2012-15 chart and therefore cannot be directly compared to it.

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 minus 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.

The VLAD chart also displays all surgical or catheter based re-interventions that occur within a 30 day episode of surgical management (see colour key on the chart in Figure 2 for types of re-intervention). These displays enable clinical teams to identify and review clusters of re-intervention following review of VLAD charts within regular governance or morbidity conferences (usually monthly). Some of these will be planned re-interventions, but the focus by the centres will be on any unplanned additional procedures that are highlighted by the VLAD chart, and any quality improvement measures that can be taken forward to avoid these in future.

Interpretation of this VLAD chart covering 2013-2016 in NCHDA

The benchmarking in this VLAD chart is based on the risk model PRAiS2. PRAiS2 is calibrated on audit data from 2009-2015, whereas PRAiS1, which was developed earlier, was calibrated based on 2009-2012. Furthermore PRAiS2 is a better and refined version of the risk model, with even better statistical performance[6]. Therefore VLAD charts using the two models on the same data would look somewhat different for the two reasons stated above.

After an initial small rise in early 2013, this VLAD chart follows a reasonably straight line from late 2013 until 2015. This indicates outcomes during this period are on a par with what would be expected based on the PRAiS2 risk model. This is not surprising since the risk model was developed using data from this era. The VLAD chart from 2015-2016 rises above the baseline, indicating the 30-day outcomes during this period, the most recent one year, which includes data that was not used to develop the risk model, were better than expected.

4.5 Antenatal detection and diagnosis of congenital heart disease

Although there are differences between countries (Table 8), overall antenatal detection rates continue to improve (Figure 3).

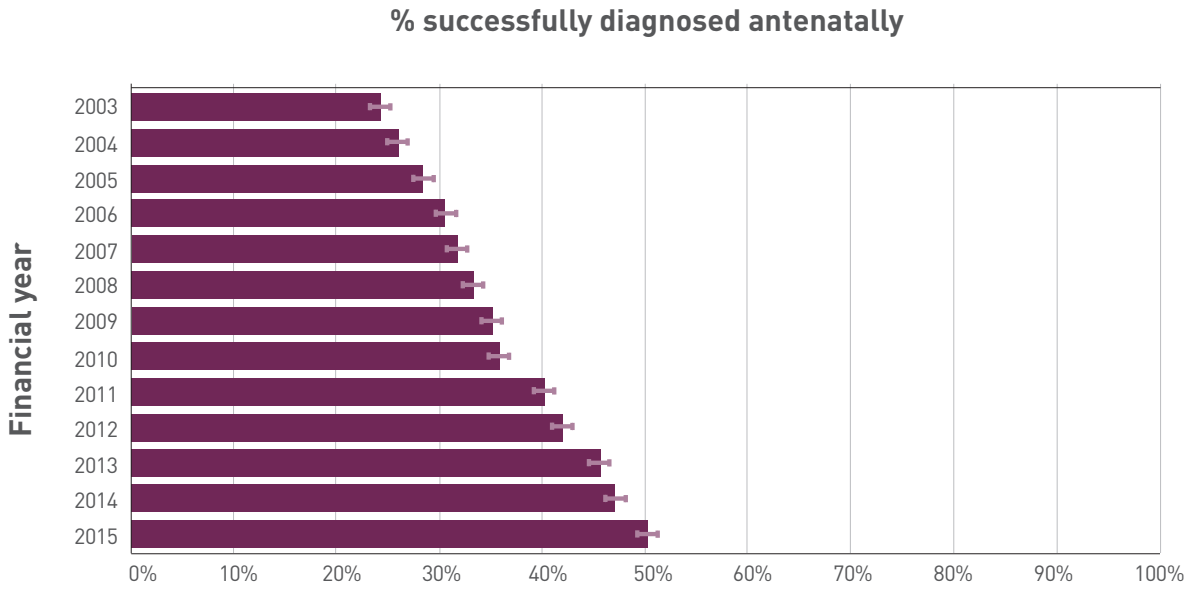
These national differences are also reflected regionally across the UK (Figure 4a and 4b). Antenatal diagnosis rates are higher in the UK than in the US between 2006 and 2012, although the gap has narrowed in recent years (Figure 5).

Table 8. Detection rates

Country	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16
England	38.1%	40.0%	42.5%	46.9%	47.1%	49.8%
Ireland (RoI)	21.8%	37.0%	32.6%	38.1%	49.3%	53.8%
N Ireland	31.6%	36.0%	33.8%	38.6%	50.0%	47.1%
Scotland	29.7%	37.3%	46.6%	37.6%	44.9%	43.1%
Wales	47.3%	60.9%	56.1%	54.7%	49.4%	58.9%
UK and RoI (overall)	36.1%	40.3%	42.2%	45.7%	47.3%	50.4%

The value shown is the percentage of eligible cases that were successfully diagnosed antenatally, i.e. those cases that required a surgical or interventional procedure during infancy. For the denominator of the number of cases that could have been picked up, please see the Tables in Appendix 4. 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.

Fig 3. Overall average % successfully diagnosed antenatally from 2003 to 2015 (financial years).



Antenatal diagnosis rates continue to rise and regional variation has reduced. Detection rates are currently highest in parts of Wales, the Southeast and Northern England, whilst lowest in Shropshire and Staffordshire, and Devon and Cornwall (see Appendix 4).

Figures 4a and 4b show the regional distribution of successful antenatal diagnosis across the UK and RoI. The data in the maps relate to Appendix 4a and 4b, which show a breakdown of antenatal diagnosis across local area teams.

Fig 4a: Regional distribution of successful antenatal diagnosis across UK and Republic of Ireland 2015-2016

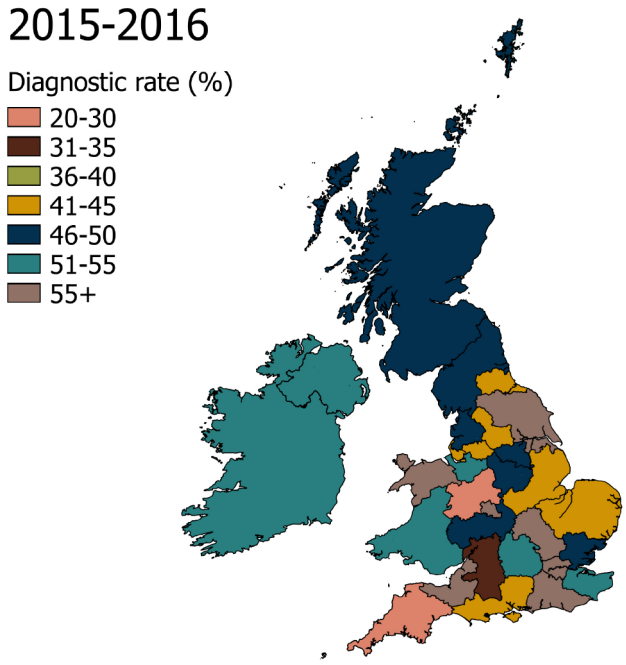


Fig 4b: Regional distribution of successful antenatal diagnosis across UK and Republic of Ireland 2013-2016

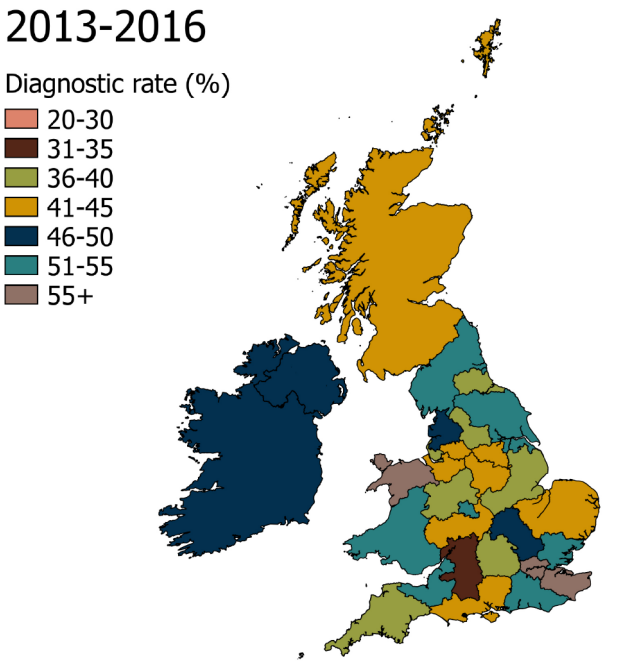
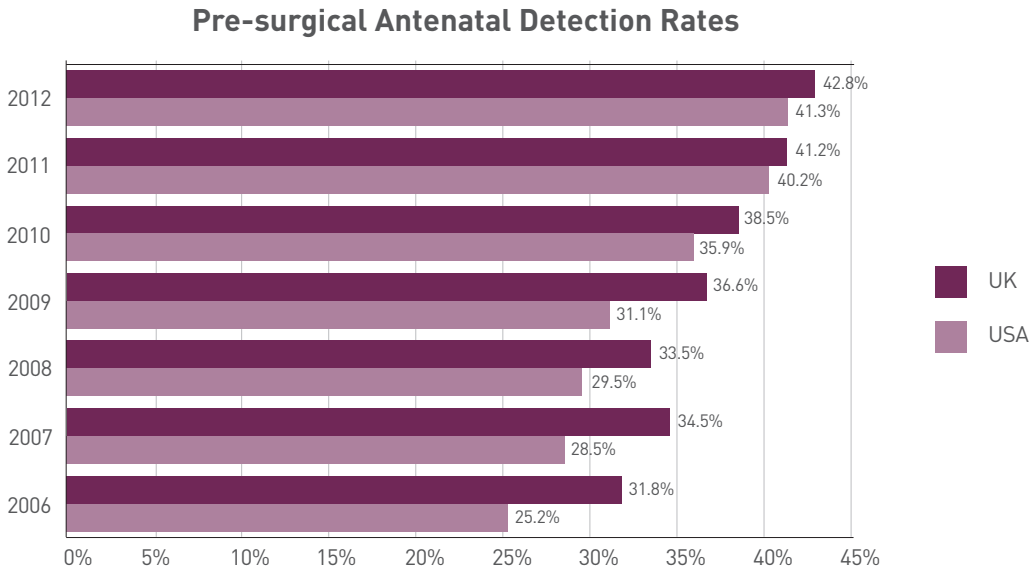


Fig 5: Pre-surgical antenatal detection rates: comparison of UK and USA 2006-2012



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).[29]

Note: The US data are based on 91 of the 125 centres (73%) undertaking CHD surgery in the US, and are based on the percentage of infants requiring cardiovascular surgery at under 6 months of age.

29. 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

Our key focus areas for 2017-18 continue to be:

- **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 have started to work further on this 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.

- **Focus on procedural morbidity.**
  In 2014, the NCHDA dataset was reviewed to ensure that the data collected continue 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: post-operative 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 ensure robust data quality and completeness, as recommended by the NCHDA Steering Committee, BCCA and SCTS. We expect to publish data on these new fields after the first three-year cycle has been completed in our 2015-18 report.

- **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 accounts for factors or comorbidities which are specific to 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, pre-procedural New York Heart Association functional class, smoking status and diabetes status, as well as evidence of pre-procedural ischaemic heart disease or pulmonary disease. We expect to publish data on these new fields after the first three-year cycle has completed in our 2015-18 report. Next year, we also plan to report on adult CHD outcomes using the published Society of Thoracic Surgeons model, although adjustments will need to be made as details at procedural level are not identical between the two models.

- **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 were added to the NCHDA dataset in April 2015 to capture this information (i.e. 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.

Over the next three years quality improvement will be a priority for NICOR. In the first phase, NICOR will focus on improving the information we provide to ensure our outputs generate quality improvement. During the second phase we will work more closely with hospitals to support quality improvement priorities. Quality improvement opportunities include:

- **Specific Procedures.**
  The congenital steering committee will continue to iteratively review and refine the specific procedure algorithm in order to ensure it captures the widest possible range of procedures and that it is updated to reflect the continuous evolution of this cutting-edge speciality by expanding to include any novel procedures that are introduced, as well as fully reporting all electrophysiological procedural data submitted to the audit as a separate procedural type.

- **90 day life status for all major cardiac surgical and interventional procedures.**
  NCHDA 30-day outcomes uses ONS data in parallel with hospital reported discharge outcomes 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 a coroner's inquest and the time frame for inquest conclusion can vary between 6 weeks and 2 years, meaning that ONS supplied life status as received by NICOR may not be accurate for at least 6 months if not longer after an individual's death. During that period life status will be reported incorrectly by ONS as "alive".

  In the last year the NCHDA has undertaken a study to better understand this issue. In 2013-14 there were 91 discrepancies likely to potentially bias the results reported as 90-day post-procedural mortality outcomes. NICOR is seeking approval from NHS Digital 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 have completed a summary report of this investigation of the impact of delays on receiving 90-day life status, which will be available on the NICOR website in due course.

- **Long-term outcomes by diagnosis.**
  The importance of extending the audit of outcomes beyond 30 days or beyond the immediate operative stay was demonstrated in a recent study based on linked NCHDA and PICANet[30] data that demonstrated the rate of post discharge mortality rate was 3.2% in infants with CHD. This has informed national guidelines on the care of infants undergoing intervention for CHD, as reported in https://www.ncbi.nlm.nih.gov/books/NBK363028/

  The NCHDA Steering Committee further 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 ran 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). The hypoplastic left heart project has been completed and has been submitted for publication. Further funding for this work stream is currently being sought.

- **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 have already been a guide as to the direction of future morbidity monitoring within the audit – please read the project web pages for further details. In the meantime, key morbidity fields have been introduced in April 2017 to capture post-procedural morbidity after both surgery and interventions related to this study. We expect to publish data on these new fields in our 2015-18 report.

- **Patient and public involvement.**
  Currently NCHDA has a patient-parent lay representative member on its Steering Committee and NICOR has a dedicated Public Patient Engagement (PPE) coordinator who is working across the whole audit programme. From July 1st 2017, PPE will be at the heart of the decision making process. A Patient Advisory Group (PAG) will be set up as well as a wider patient involvement network that will be involved in a number of activities including user testing. It is envisaged that the Chair of the PAG will also sit on the high level Stakeholder Board, and there will be patient/public representation on other strategic working groups and committees.

- **Improve the information on antenatal diagnosis and outcome, linking to postnatal outcomes.**
  Next year NCHDA will be publishing similar regional data to that already reported, but targeting specific congenital heart lesions, such as hypoplastic left heart syndrome and transposition of the great arteries so that efforts in training can be further focussed. This should help to further reduce regional variation in antenatal detection of fetal heart malformations.

- **NCHDA Fetal Cardiac audit extension.**
  This aims to improve the information on antenatal diagnosis and outcome, linking to postnatal outcomes, so as to report outcomes by congenital heart disease diagnosis rather than procedure for the first time. Currently antenatal diagnosis is reported by the specialist centres as part of their audit return with a simple Yes/No response to whether a patient was diagnosed antenatally. We are in the process of implementing this extension to the audit to include additional maternal and new-born demographics, so as to enable tracking of those with congenital heart malformations from prenatal diagnosis through to infancy and beyond, linking to the main NCHDA dataset if a procedure is undertaken. This will include tracking antenatal outcomes such as in uterine death and termination of pregnancy. The fetal database extension is targeting 10 main lesions which are deemed important and achievable by the National Fetal Cardiology Group (see Appendix 6).

  This expansion is supported by Public Health England, HQIP and NHS England. Part of this project is for there to be a bi-directional link to the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) for data validation and case ascertainment purposes. Permissions and a data sharing agreement are now in place to allow the sharing of NCHDA data with NCARDRS. The reverse data sharing agreement to allow NCARDRS data to quality assure NCHDA antenatal data will follow in 2017.

  There are 37 data fields: maternal demographics (10 fields), pregnancy and date of fetal diagnosis (9 fields), fetal cardiac and extracardiac or syndromic diagnoses (4 fields), fetal outcome (2 fields), postnatal diagnoses (3 fields), and neonatal demographics, weight and outcome (8 fields). There will be a link to the NCHDA postnatal procedural database when appropriate.

  This linkage is key to moving towards a diagnosis based database, rather than relying only on the current procedure-led approach to assess outcomes for quality assurance and improvement initiatives.

30. Paediatric Intensive Care audit Network (PICANet) is an international audit that collects information on all children admitted to paediatric intensive care in the UK and the Republic of Ireland. Further information can be found here: http://www.picanet.org.uk/

- **Improving data submission and verification.**
  A web enabled version of the data collection system has been developed and will be available from the Autumn of 2017 for use by all centres. The framework being used encompasses modern technologies where it supports multiple browsers, which in turn can be run on PCs or portable devices. NICOR is working towards a common software development approach for the audits. The benefits will include a common look and feel via a web based system, improved software quality and allow for quicker development. In addition, a real-time data completeness tool highlighting data inconsistency and missing values will give centres immediate feedback on the quality of data submitted.
- **Improving the NCHDA Public Website.**
  Dissemination/Reporting: NICOR is developing a new interactive public website to communicate the national cardiac audit results, including those from the NCHDA. Patient groups, clinicians and commissioners will be involved in the design of the reports which are due to go live in 2018.

6. Recommendations

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

In order to ensure Data Quality is of the highest standard for quality assurance and quality improvement initiatives, we recommend that you:

1. Ensure that your Specialist Surgical Centre has a minimum of 1 Whole Time Equivalent (WTE) dedicated paediatric cardiac surgery/cardiology Database Manager (DBM) at Band 7 Agenda for Change, with at least 1 WTE assistant (at least Band 6), 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).[31]

2. Ensure there are sufficient resources allocated to, and sufficient processes put in place, to fully support national clinical audit activity, including local Information Technology support and software that fully accommodates the NCHDA dataset for timely submission of data and verification of data quality. Each DBM should have their own user ID and password to access the NCHDA database and make timely submissions.

3. Ensure all patients undergoing CHD procedures have a preceding congenital cardiology Multidisciplinary Team (MDT) meeting, including all adult patients, in accordance with the congenital cardiology service specification published as part of the NHS England New CHD Review (2015), thereby minimising occasional practice for adult CHD procedures.[32]

4. 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 better data completeness and data quality. Each clinical audit should have an identified Clinical Audit Lead assigned to support this activity. The clinical lead should have protected time to be involved with the regular validation of data to be submitted, as well as PRAiS2 analysis.

5. Ensure all operators regularly review their data submitted to the NCHDA to improve timeliness and accuracy. This should be on at least a quarterly basis but monthly for large centres. Trusts should engage with the NCHDA annual validation process and site visits, considering and implementing recommendations therein. Relevant clinicians (consultants and trainees) should engage with robust data quality assurance and completeness procedures. All centres undertaking congenital cardiology procedures should submit data to the NCHDA, including adult patients with CHD.

II. Chief Executives, Medical Directors and Clinical Leads at Centres providing antenatal screening for congenital heart malformations

We recommend that you:

1. Target quality initiatives such as staff training and optimisation of sonographic equipment, to enable improvements in antenatal ultrasound scanning detection rates of congenital cardiac conditions. This is in accordance with NHS Fetal Anomaly Screening Programme guidance and recommendations,[33] and the Fetal Cardiology Standards of the British Congenital Cardiac Association.[34]

2. Ensure that feedback mechanisms and links are in place between the paediatric, cardiology and antenatal ultrasound scanning departments to enable learning relating to cases of congenital heart disease where antenatal sonography failed to detect the defect. This will be facilitated by the NHCDA fetal cardiac screening results being made fully available to the UK National Fetal Cardiology Group, so that its members can target individual centres whose performance needs to improve.

III. Congenital Cardiology Clinical Audit Teams

We recommend that you:

1. Ensure that your Specialist Surgical Centre has a minimum of 1 Whole Time Equivalent (WTE) dedicated paediatric cardiac surgery/cardiology Database Manager (DBM) at Band 7 Agenda for Change, with at least 1 WTE assistant (at least Band 6), 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).[12]

2. Ensure there are sufficient resources allocated to, and sufficient processes put in place, to fully support national clinical audit activity, including local Information Technology support and software that fully accommodates the NCHDA dataset for timely submission of data and verification of data quality. Each DBM should have their own user ID and password to access the NCHDA database and make timely submissions.

3. Ensure all patients undergoing CHD procedures have a preceding congenital cardiology Multidisciplinary Team (MDT) meeting, including all adult patients, in accordance with the congenital cardiology service specification published as part of the NHS England New CHD Review (2015), thereby minimising occasional practice for adult CHD procedures.[12]

4. 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

31. https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf
32. https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf
33. https://www.gov.uk/guidance/fetal-anomaly-screening-programme-overview
34. http://www.bcs.com/documents/Fetal_Cardiology_Standards_Final_Version_March_2010.pdf

better data completeness and data quality. Each clinical audit should have an identified Clinical Audit Lead assigned to support this activity. The clinical lead should have protected time to be involved with the regular validation of data to be submitted, as well as PRAiS2 analysis.

5. Ensure all operators regularly review their data submitted to the NCHDA to improve timeliness and accuracy. This should be on at least a quarterly basis but monthly for large centres. Trusts should engage with the NCHDA annual validation process and site visits, considering and implementing recommendations therein. Relevant clinicians (consultants and trainees) should engage with robust data quality assurance and completeness procedures. All centres undertaking congenital cardiology procedures should submit data to the NCHDA, including adult patients with CHD.

IV. Patients and Public

1. This report, along with the NCHDA website, allows you to review the activity of local centres as well as outcomes, such as survival following major procedures. We also report a comparison of risk adjusted mortality for whole program surgical activity in children for all paediatric centres. We identify alerts and alarms, publishing subsequent responses from specialist centres.

2. Families and patients, along with other interested parties, are strongly encouraged to view the recently launched 'Understanding Children's Heart Surgery Outcomes' website: http://childrensheartsurgery.info/ This gives a comprehensive and accessible explanation of the way NCHDA has analysed whole centre outcomes using PRAiS software and the underlying survival statistics. It also provides an understanding of why risk adjusted outcomes are needed for procedures involving congenital heart malformations. In essence, knowing and understanding the risk factors for each child allows us to predict the percentage of children within a group that will survive, even though we cannot predict exactly whether individual children will survive. The NCHDA uses a statistical formula to combine data on these risk factors for all the children a hospital has treated over the previous three years to give a predicted range for the overall proportion of survivors for that specific hospital and time period. The formula is also used to calculate an extended predicted range for survival for each hospital. The audit body then compares the survival rate achieved by a hospital with its predicted and extended predicted range.

Appendix 1a: 30-day outcomes by age group for all procedures 2013-16†

Procedures 2013-16	ALL AGES						PAEDIATRIC						ADULT				
	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival		Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival		Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival
Overall activities by type of procedure	33754	33073	669	12	98.00%		24042	23464	568	10	97.60%		9712	9609	101	*	98.90%
Surgical activities total	17481	17005	471	5	97.3%		14076	13668	403	5	97.1%		3405	3337	68	0	98.0%
Bypass	13771	13468	301	*	97.80%		10562	10322	238	*	97.70%		3209	3146	63	0	98.00%
Non-bypass	3263	3151	111	*	96.60%		3097	2985	111	*	96.40%		166	166	0	0	100.00%
Hybrid††	165	149	14	*	90.30%		155	139	14	*	89.70%		10	10	0	0	100.00%
Primary ECMO††	114	86	28	0	75.40%		106	80	26	0	75.50%		8	6	*	0	75.00%
Lung Transplant††	21	21	0	0	100.00%		19	19	0	0	100.00%		*	*	0	0	100.00%
Ventricular Assist Device (VAD)††	147	130	17	0	88.40%		137	123	14	0	89.80%		10	7	*	0	70.00%
Primary ECMO/Lung Transplant/ VAD total	282	237	45	0	84.0%		262	222	40	0	84.7%		20	15	5	0	75.0%
Catheter/Electrophysiology total	16273	16068	198	7	98.74%		9966	9796	165	5	98.29%		6307	6272	33	*	99.4%
Interventional	10962	10802	154	6	98.50%		7051	6912	135	*	98.00%		3911	3890	19	*	99.50%
Implantable Cardioverter Defibrillator(AICD)	352	351	*	0	99.70%		92	91	*	0	98.90%		260	260	0	0	100.00%
Pacemaker procedures	1051	1040	11	0	99.00%		462	456	6	0	98.70%		589	584	5	0	99.20%
EP & ablation & diagnostic EP	2277	2273	*	*	99.80%		1278	1277	0	*	99.90%		999	996	*	0	99.70%
Diagnostic catheter (2015-2016 only)†	1631	1602	29	0	98.20%		1083	1060	23	0	97.90%		548	542	6	0	98.90%

†Diagnostic catheter data only added to the data set in 2015-2016.

††It is important to note that the figures in the table refer to procedures undertaken and not to individual patients. Hence life status figures may include the same patient who has had more than one procedure and either survived, or not survived.

†††It is also important not to compare this crude mortality from year to year as the casemix changes and it is not risk adjusted.

*Numbers lower than 5

Appendix 1b: 30-day outcomes by age group for Specific Procedures†

Specific procedures allocation	ALL AGES					PAEDIATRIC					ADULT				
	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival
Specific procedures allocated	26546	26132	405	9	9 8.4%	18687	18340	340	7	98.1%	7859	7792	65	*	99.1%
No specific procedure allocated	5585	5343	239	*	95.7%	4205	3991	211	*	94.9%	1380	1352	28	0	98.0%
% of procedures allocated	82.6%					81.6%					85.1%				-
Surgical															
Anomalous coronary artery repair	51	51	0	0	100.0%	38	38	0	0	100.0%	13	13	0	0	100.0%
Aortic root replacement (not Ross)	223	216	7	0	96.9%	35	34	*	0	97.1%	188	182	6	0	96.8%
Aortic valve repair	310	307	*	0	99.0%	219	217	*	0	99.1%	91	90	*	0	98.9%
Aortic Valve Replacement - non Ross	525	513	12	0	97.7%	48	46	*	0	95.8%	477	467	10	0	97.9%
Aortic valve replacement - Ross	155	155	0	0	100.0%	95	95	0	0	100.0%	60	60	0	0	100.0%
Aortopulmonary window repair	28	28	0	0	100.0%	28	28	0	0	100.0%	0	0	0	0	-
Arterial shunt	320	293	26	*	91.6%	318	291	26	*	91.5%	*	*	0	0	100.0%
Arterial switch (for isolated transposition)	401	398	*	*	99.3%	400	397	*	*	99.2%	*	*	0	0	100.0%
Arterial switch + aortic arch obstruction repair (with-without VSD closure)	64	56	8	0	87.5%	64	56	8	0	87.5%	0	0	0	0	-

Specific procedures allocation	ALL AGES					PAEDIATRIC					ADULT				
	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival
Arterial switch + VSD closure	161	159	*	0	98.8%	161	159	*	0	98.8%	0	0	0	0	-
ASD repair	830	828	*	0	99.8%	555	555	0	0	100.0%	275	273	*	0	99.3%
Atrioventricular septal defect (complete) repair	528	524	*	0	99.2%	519	515	*	0	99.2%	9	9	0	0	100.0%
Atrioventricular septal defect (partial) repair	279	277	*	0	99.3%	224	222	*	0	99.1%	55	55	0	0	100.0%
Atrioventricular septal defect and tetralogy repair	40	39	*	0	97.5%	40	39	*	0	97.5%	0	0	0	0	-
Bidirectional cavopulmonary shunt	682	670	12	0	98.2%	670	661	9	0	98.7%	12	9	*	0	75.0%
Cardiac conduit replacement	189	185	*	0	97.9%	141	138	*	0	97.9%	48	47	*	0	97.9%
Cor triatriatum repair	39	39	0	0	100.0%	35	35	0	0	100.0%	*	*	0	0	100.0%
Fontan procedure	657	650	7	0	98.9%	650	643	7	0	98.9%	7	7	0	0	100.0%
Heart Transplant	123	116	7	0	94.3%	98	94	*	0	95.9%	25	22	*	0	88.0%
Interrupted aortic arch repair	71	71	0	0	100.0%	71	71	0	0	100.0%	0	0	0	0	-
Isolated coarctation/ hypoplastic aortic arch repair	761	751	10	0	98.7%	744	734	10	0	98.7%	17	17	0	0	100.0%
Isolated Pulmonary trunk band	328	322	6	0	98.2%	328	322	6	0	98.2%	0	0	0	0	-
Isolated RV to PA conduit construction	333	325	8	0	97.6%	273	266	7	0	97.4%	60	59	*	0	98.3%
Mitral valve repair	269	262	7	0	97.4%	170	167	*	0	98.2%	99	95	*	0	96.0%
Mitral valve replacement	229	215	14	0	93.9%	124	114	10	0	91.9%	105	101	*	0	96.2%
Multiple VSD Closure	47	47	0	0	100.0%	47	47	0	0	100.0%	0	0	0	0	-

Specific procedures allocation	ALL AGES					PAEDIATRIC					ADULT				
	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival
Norwood procedure (Stage 1)	323	288	35	0	89.2%	323	288	35	0	89.2%	0	0	0	0	-
PDA ligation (surgical)	892	856	36	0	96.0%	892	856	36	0	96.0%	0	0	0	0	-
Pulmonary atresia VSD repair	99	97	*	0	98.0%	99	97	*	0	98.0%	0	0	0	0	-
Pulmonary valve replacement	860	851	9	0	99.0%	195	193	*	0	99.0%	665	658	7	0	98.9%
Pulmonary vein stenosis procedure	88	81	7	0	92.0%	70	63	7	0	90.0%	18	18	0	0	100.0%
Rastelli - REV procedure	59	57	*	0	96.6%	58	56	*	0	96.6%	*	*	0	0	100.0%
Repair of total anomalous pulmonary venous connection	208	193	15	0	92.8%	205	190	15	0	92.7%	*	*	0	0	100.0%
Ross-Konno procedure	64	61	*	0	95.3%	53	50	*	0	94.3%	11	11	0	0	100.0%
Senning or Mustard procedure	5	5	0	0	100.0%	5	5	0	0	100.0%	0	0	0	0	-
Sinus Venosus ASD and-or PAPVC repair	353	350	*	0	99.2%	149	146	*	0	98.0%	204	204	0	0	100.0%
Subvalvar aortic stenosis repair	523	522	*	0	99.8%	441	440	*	0	99.8%	82	82	0	0	100.0%
Supravalvar aortic stenosis repair	90	89	*	0	98.9%	81	80	*	0	98.8%	9	9	0	0	100.0%
TAPVC Repair + Arterial Shunt	*	*	*	0	25.0%	*	*	*	0	25.0%	0	0	0	0	-
Tetralogy and Fallot-type DORV repair	887	884	*	0	99.7%	880	877	*	0	99.7%	7	7	0	0	100.0%
Tetralogy with absent pulmonary valve repair	18	18	0	0	100.0%	18	18	0	0	100.0%	0	0	0	0	-
Tricuspid valve repair	245	239	6	0	97.6%	99	95	*	0	96.0%	146	144	*	0	98.6%

Specific procedures allocation	ALL AGES					PAEDIATRIC					ADULT				
	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival
Tricuspid valve replacement	101	97	*	0	96.0%	21	19	*	0	90.5%	80	78	*	0	97.5%
Truncus and interruption repair	10	9	*	0	90.0%	10	9	*	0	90.0%	0	0	0	0	-
Truncus arteriosus repair	85	81	*	0	95.3%	85	81	*	0	95.3%	0	0	0	0	-
Unifocalisation procedure (with/ without shunt)	29	26	*	0	89.7%	29	26	*	0	89.7%	0	0	0	0	-
Vascular ring procedure	215	214	*	0	99.5%	208	207	*	0	99.5%	7	7	0	0	100.0%
VSD Repair	1020	1019	*	0	99.9%	990	989	*	0	99.9%	30	30	0	0	100.0%
Catheter interventions															
ASD closure (catheter)	2112	2108	*	*	99.80%	803	802	0	*	99.9%	1309	1306	*	*	99.8%
PDA closure (catheter)	1720	1716	*	0	99.80%	1630	1626	*	0	99.8%	90	90	0	0	100.0%
PFO closure (catheter)	1375	1372	*	0	99.80%	17	17	0	0	100.0%	1358	1355	*	0	99.8%
VSD closure (catheter)	114	110	*	0	96.50%	80	78	*	0	97.5%	34	32	*	0	94.1%
Balloon atrial septostomy	505	468	36	*	92.70%	501	467	33	*	93.2%	*	*	*	0	25.0%
Balloon dilation native coarctation	83	80	*	0	96.40%	77	74	*	0	96.1%	6	6	0	0	100.0%
Balloon Dilation of Aortic Valve	310	304	6	0	98.10%	294	289	5	0	98.3%	16	15	*	0	93.8%
Balloon Dilation of Pulmonary Artery	661	653	7	*	98.80%	608	600	7	*	98.7%	53	53	0	0	100.0%
Balloon Dilation of Pulmonary Valve	696	689	7	0	99.00%	616	609	7	0	98.9%	80	80	0	0	100.0%
Blade atrial septostomy	6	*	*	0	50.00%	6	*	*	0	50.0%	0	0	0	0	-
Cardiac conduit balloon dilation or stenting	154	153	*	0	99.40%	124	124	0	0	100.0%	30	29	*	0	96.7%

Specific procedures allocation	ALL AGES					PAEDIATRIC					ADULT				
	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival	Procedures	Alive at 30d	Dead at 30d	Unknown	30d Survival
Coarctation stenting	365	363	*	0	99.50%	134	132	*	0	98.5%	231	231	0	0	100.0%
Duct Stenting	110	101	9	0	91.80%	107	98	9	0	91.6%	*	*	0	0	100.0%
Pulmonary artery stenting	496	488	7	*	98.40%	415	407	7	*	98.1%	81	81	0	0	100.0%
Pulmonary valvotomy (radiofrequency)	77	75	*	0	97.40%	77	75	*	0	97.4%	0	0	0	0	-
Pulmonary vein catheter procedure	56	53	*	0	94.60%	47	44	*	0	93.6%	9	9	0	0	100.0%
Recoarctation angioplasty	240	236	*	0	98.30%	223	219	*	0	98.2%	17	17	0	0	100.0%
RVOT Stenting	160	154	6	0	96.20%	141	135	6	0	95.7%	19	19	0	0	100.0%
Systemic-to-pulmonary collateral artery (MAPCA) related catheter procedure	179	175	*	0	97.80%	166	162	*	0	97.6%	13	13	0	0	100.0%
Transcatheter PVR	201	198	*	*	98.50%	38	38	0	0	100.0%	163	160	*	*	98.2%
Electrophysiological															
Biventricular pacing and CRT	77	77	0	0	100.00%	*	*	0	0	100.0%	73	73	0	0	100.0%
Implantable Cardioverter Defibrillator	251	250	*	0	99.60%	83	82	*	0	98.8%	168	168	0	0	100.0%
Pacemaker implant	714	712	*	0	99.70%	341	341	0	0	100.0%	373	371	*	0	99.5%
Radiofrequency ablation for tachyarrhythmia	2063	2059	*	*	99.80%	1145	1144	0	*	99.9%	918	915	*	0	99.7%

ASD: Atrial Septal Defect; CRT: Cardiac Resynchronisation Therapy; DORV: Double Outlet Right Ventricle; MAPCA: Major systemic-to-pulmonary collateral artery(ies); PA: Pulmonary Artery; PAPVC: Partial Anomalous Pulmonary Venous Connection; PDA: Patent Ductus Arteriosus; PFO: Patent Foramen Ovale; REV: Réparation à l'Etage Ventriculaire; RV: Right Ventricle; TAPVC: Total Anomalous Pulmonary Venous Connection; VSD: Ventricular Septal Defect

†It is important to note that the figures in the table refer to procedures undertaken and not to individual patients. Hence life status figures may include the same patient who has had more than one procedure and either survived, or not survived.

Appendix 1c: 2013-2016 Surgical Activity for all major centres

Hospital Name	Hospital Code	2013-14	2014-15	2015-16
Belfast Royal Victoria Hospital	RVB	72	54	46
Birmingham Children's Hospital	BCH	514	502	503
Birmingham Queen Elizabeth Hospital	QEB	118	86	60
Bristol Royal Hospital For Children	BRC	391	409	445
Dublin Our Lady's Children's Hospital	OLS	355	353	343
Glasgow Golden Jubilee National Hospital	GJH	142	86	90
Glasgow Royal Hospital for Children	RHS	283	261	235
Leeds General Infirmary	LGI	477	497	493
Leicester Glenfield Hospital	GRL	299	282	323
Liverpool Alder Hey Hospital	ACH	394	375	357
Liverpool Heart and Chest Hospital	BHL	23	20	11
† London (Barts Heart Centre)	SBH	0	0	60
London (Evelina London Children's Hospital)	GUY	534	511	513
London (Great Ormond Street Hospital for Children)	GOS	728	717	690
London (Harley Street Clinic)	HSC	188	114	113
London (Royal Brompton Hospital)	NHB	541	516	524
† London (University College Hospital)	UCL	81	67	*
Manchester Royal Infirmary	MRI	99	89	88
Newcastle Freeman Hospital	FRE	391	367	324
Southampton Wessex Cardiothoracic Centre	SGH	382	367	391

Note: Surgical procedures comprise bypass, non-bypass, hybrid, lung transplant, Ventricular Assist Device (VAD) and primary Extracorporeal Membranous Oxygenation mechanical life support (ECMO) procedures

†All CHD activity at University College Hospital, which was housed at The Heart Hospital, moved to the Barts Heart Centre in April 2015.

*Numbers lower than 5

Appendix 2: Outcomes based research using NCHDA data

Publications reporting the use of National Congenital Heart Disease Audit in quality assurance and quality improvement initiatives 2015-17

Brown KL, Wray J, Knowles RL, Crowe S, Tregay J, Ridout D, Barron DJ, Cunningham D, Parslow R, Franklin R, Barnes N, Hull S, Bull C. Infant deaths in the UK community following successful cardiac surgery: building the evidence base for optimal surveillance, a mixed-methods study. Southampton (UK): NIHR Journals Library; 2016 May.

Brown KL, Rogers L, Barron DJ, Tsang V, Anderson D, Tibby S, Witter T, Stickley J, Crowe S, English K, Franklin RC, Pagel C. Incorporating Comorbidity Within Risk Adjustment for UK Pediatric Cardiac Surgery. Ann Thorac Surg. 2017 Mar 15. pii: S0003-4975(16)31826-4.

Crowe S, Knowles R, Wray J, Tregay J, Ridout DA, Utley M, Franklin R, Bull CL, Brown KL. BMJ Open. 2016 Jun 6; 6(6):e010363. Identifying improvements to complex pathways: evidence synthesis and stakeholder engagement in infant congenital heart disease. doi: 10.1136/bmjopen-2015-010363.

Crowe S, Ridout DA, Knowles R, Tregay J, Wray J, Barron DJ, Cunningham D, Parslow RC, Utley M, Franklin R, Bull C, Brown KL. Death and Emergency Readmission of Infants Discharged After Interventions for Congenital Heart Disease: A National Study of 7643 Infants to Inform Service Improvement. J Am Heart Assoc. 2016 May 20; 5(5). pii: e003369. doi: 10.1161/JAHA.116.003369.

Dorobantu DM, Pandey R, Sharabiani MT, Mahani AS, Angelini GD, Martin RP, Stoica SC. Indications and results of systemic to pulmonary shunts: results from a national database. Eur J Cardiothorac Surg. 2016 Jun; 49(6):1553-63.

Fiorentino F, Stickley J, Dorobantu D, Pandey R, Angelini G, Barron D, Stoica S. Early Reoperations in a 5-Year National Cohort of Pediatric Patients With Congenital Heart Disease. Ann Thorac Surg. 2016 Apr; 101(4):1522-9. doi: 10.1016/j.athoracsur.2015.12.039. Epub 2016 Feb 26.

Pagel C, Jesper E, Thomas J, Blackshaw E, Rakow T, Pearson M, Spiegelhalter D. Understanding Children's Heart Surgery Data: A Cross-Disciplinary Approach to Codevelop a Website. Ann Thorac Surg. 2017 Mar 15. pii: S0003-4975(16)31821-5

Rogers L, Brown KL, Franklin RC, Ambler G, Anderson D, Barron DJ, Crowe S, English K, Stickley J, Tibby S, Tsang V, Utley M, Witter T, Pagel C. Improving Risk Adjustment for Mortality After Pediatric Cardiac Surgery: The UK PRAiS2 Model. Ann Thorac Surg. 2017 Mar 15. pii: S0003-4975(16)31828-8.

Sharabiani MT, Dorobantu DM, Mahani AS, Turner M, Peter Tometzki AJ, Angelini GD, Parry AJ, Caputo M, Stoica SC. Aortic Valve Replacement and the Ross Operation in Children and Young Adults. J Am Coll Cardiol. 2016 Jun 21; 67(24):2858-70.doi: 10.1016/j.jacc.2016.04.021.

Appendix 3a and 3b

Appendix 3a: Hospitals undertaking paediatric and ACHD Procedures

DQI% for 13/14 data based on the 20 case note review May – Nov 2014				
Hospital	**Hospital**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Belfast Royal Victoria Hospital	**RVB**	**95.75**	**96.75**	**95.25**
Birmingham Children's Hospital	**BCH**	**96.5**	**96.75**	**97**
Bristol Royal Hospital for Children	**BRC**	**96.50**	**98.25**	93.25
Dublin Our Lady's Children's Hospital	**OLS**	**96.5**	**96.25**	**96.5**
Glasgow Royal Hospital for Children	**RHS**	**98.5**	**97.5**	**99.5**
Leeds General Infirmary	**LGI**	**97.75**	**95.25**	**99**
Leicester Glenfield Hospital	**GRL**	90.5	94	85.5
Liverpool Alder Hey Hospital	**ACH**	94.75	**96**	92.25
London Evelina London Children's Hospital	**GUY**	**97**	**98**	94.25
London Great Ormond Street for Children	**GOS**	**99.5**	**99.5**	**99.5**
London Harley Street Clinic	**HSC**	**95.75**	**96.5**	94.5
London Royal Brompton Hospital	**NHB**	**98**	**99.25**	**96.25**
Newcastle Freeman	**FRE**	**96.75**	**97.25**	**95.5**
Southampton Wessex Cardiothoracic Centre	**SGH**	**98**	**98.25**	**98.25**

DQI% for 14/15 data based on the 20 case note review May 15 – Feb 16				
Hospital	**Hospital**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Belfast Royal Victoria Hospital	**RVB**	**98.75**	**99.75**	**98.25**
Birmingham Children's Hospital	**BCH**	**98.5**	**98.5**	**98**
Bristol Royal Hospital for Children	**BRC**	94.50	**95**	94
Dublin Our Lady's Children's Hospital	**OLS**	**97.25**	**97.75**	**96**
Glasgow Royal Hospital for Children	**RHS**	**98.5**	**99.5**	**96.5**
Leeds General Infirmary	**LGI**	**97**	**97.25**	**96**
Leicester Glenfield Hospital	**GRL**	94	92.7	**97**
Liverpool Alder Hey Hospital	**ACH**	**97.25**	**96.5**	**98**
London Evelina London Children's Hospital	**GUY**	**97.5**	**98.5**	**98**
London Great Ormond Street for Children	**GOS**	**99.5**	**99.5**	**99.5**
London Harley Street Clinic	**HSC**	94.5	**96.5**	86
London Royal Brompton Hospital	**NHB**	**99**	**98.75**	**97.75**
Newcastle Freeman	**FRE**	**97.25**	**97.25**	**97**
Southampton Wessex Cardiothoracic Centre	**SGH**	**97.5**	**98**	**97.5**

DQI% for 15/16 data based on the 20 case note review May-Nov 2016				
Hospital	**Hospital**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Belfast Royal Victoria Hospital	**RVB**	**98.25**	**98.25**	**98.5**
Birmingham Children's Hospital	**BCH**	**97.75**	**98.75**	**96.75**
Bristol Royal Hospital for Children	**BRC**	**98.60**	**99.25**	**98.25**
Dublin Our Lady's Children's Hospital	**OLS**	94.5	94.25	**95**
Glasgow Royal Hospital for Children	**RHS**	**99.25**	**98.75**	**99.25**
Leeds General Infirmary	**LGI**	**97. 75**	**98.5**	**97.25**
Leicester Glenfield Hospital	**GRL**	**97**	**97**	**97.25**
Liverpool Alder Hey Hospital	**ACH**	**95.25**	94	**96.25**
London Evelina London Children's Hospital	**GUY**	**99.25**	**99.25**	**99.5**
London Great Ormond Street for Children	**GOS**	**97**	**97.25**	**96.65**
London Harley Street Clinic	**HSC**	**95.5**	**95.5**	**93.5**
London Royal Brompton Hospital	**NHB**	**99.25**	**99.5**	**98.75**
Newcastle Freeman	**FRE**	**97.5**	**98.5**	**97**
Southampton Wessex Cardiothoracic Centre	**SGH**	**95.75**	**98**	93

Note: Above 95% is excellent as shown in bold in the above table.

Appendix 3b: Hospitals undertaking only ACHD Procedures in general

DQI% for 13/14 data based on the 20 case note review May – Nov 2014				
Hospital	**Hospital**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Basildon Essex Cardiothoracic Centre	**BAS**	Remote validation		
Birmingham Queen Elizabeth Hospital	**QEB**	77	82.25	79.75
Blackpool Victoria Hospital	**VIC**	Remote validation		
Bristol, Spire Hospital	**GHB**	Remote validation		
Royal Sussex County Hospital	**RSC**	Remote validation		
Cambridge Papworth	**PAP**	Did Not Participate		
Cardiff University Hospital of Wales	**UHW**	Remote validation		
Glasgow Golden Jubilee National Hospital	**GJH**	**97.5**	**98.5**	**95.25**
Liverpool Heart and Chest Hospital	**BHL**	Remote validation		
London University College Hospital/St Bartholomew's	**UCL**	89.5	89	88.75
London Hammersmith Hospital	**HAM**	Remote validation		
London Kings College Hospital	**KCH**	Remote validation		
London St George's Hospital	**GEO**	Remote validation		
Manchester Royal Infirmary	**MRI**	**95**	**97.75**	92.25
Nottingham City Hospital	**CHN**	Remote validation		
Sheffield Northern General Hospital	**NGS**	Remote validation		
Oxford John Radcliffe Hospital	**RAD**	Remote validation		
Stoke University Hospital of North Staffordshire	**STO**	Remote validation		
Wolverhampton Heart & Lung Centre	**NCR**	Remote validation		

DQI% for 14/15 data based on the 20 case note review May 15 – Feb 16				
Hospital	**Hospital**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Basildon Essex Cardiothoracic Centre	**BAS**	Remote validation		
Birmingham Queen Elizabeth Hospital	**QEB**	79	77	87.5
Blackpool Victoria Hospital	**VIC**	Remote validation		
Bristol, Spire Hospital	**GHB**	Remote validation		
Royal Sussex County Hospital	**RSC**	Remote validation		
Cambridge Papworth	**PAP**	Did Not Participate		
Cardiff University Hospital of Wales	**UHW**	Remote validation		
Glasgow Golden Jubilee National Hospital	**GJH**	94.5	**95.25**	94
Liverpool Heart and Chest Hospital	**BHL**	Remote validation		
London University College Hospital/St Bartholomew's	**UCL**	94.25	93.5	**95.25**
London Hammersmith Hospital	**HAM**	Remote validation		
London Kings College Hospital	**KCH**	Remote validation		
London St George's Hospital	**GEO**	Remote validation		
Manchester Royal Infirmary	**MRI**	**97**	**97.25**	**96**
Nottingham City Hospital	**CHN**	Remote validation		
Sheffield Northern General Hospital	**NGS**	Remote validation		
Oxford John Radcliffe Hospital	**RAD**	Remote validation		
Stoke University Hospital of North Staffordshire	**STO**	Remote validation		
Wolverhampton Heart & Lung Centre	**NCR**	Remote validation		

DQI% for 15/16 data based on the 20 case note review May-Nov 2016				
Hospital	**Hospital**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Basildon Essex Cardiothoracic Centre	**BAS**	Remote validation		
Birmingham Queen Elizabeth Hospital	**QEB**	75.25	66.75	89.75
Blackpool Victoria Hospital	**VIC**	Remote validation		
Bristol, Spire Hospital	**GHB**	Remote validation		
Royal Sussex County Hospital	**RSC**	Remote validation		
Cambridge Papworth	**PAP**	83.5		
Cardiff University Hospital of Wales	**UHW**	Remote validation		
Glasgow Golden Jubilee National Hospital	**GJH**	92.5	93.25	92
Liverpool Heart and Chest Hospital	**BHL**	Remote validation		
London University College Hospital/St Bartholomew's	**UCL/ SBH**	93.25	91.75	93.75
London Hammersmith Hospital	**HAM**	Remote validation		
London Kings College Hospital	**KCH**	Remote validation		
London St George's Hospital	**GEO**	Remote validation		
Manchester Royal Infirmary	**MRI**	**97.7**	**97**	**96.75**
Nottingham City Hospital	**CHN**	Remote validation		
Sheffield Northern General Hospital	**NGS**	Remote validation		
Oxford John Radcliffe Hospital	**RAD**	Remote validation		
Stoke University Hospital of North Staffordshire	**STO**	Remote validation		
Wolverhampton Heart & Lung Centre	**NCR**	Remote validation		

Note: Above 95% is excellent as shown in bold in the above table.

Appendix 4a: Antenatal Diagnosis 2015-16

Local Area Team (LAT)	Cases	Diagnosed antenatally (%)
England (LAT not known)	106	50.9%
Q44. Cheshire, Warrington and Wirral	33	51.5%
Q45. Durham, Darlington and Tees	59	45.8%
Q46. Greater Manchester	99	42.4%
Q47. Lancashire	46	47.8%
Q48. Merseyside	42	42.9%
Q49. Cumbria, Northumberland, Tyne and Wear	102	48.0%
Q50. North Yorkshire and Humber	53	60.4%
Q51. South Yorkshire and Bassetlaw	66	50.0%
Q52. West Yorkshire	114	44.7%
Q53. Arden, Herefordshire and Worcestershire	83	48.2%
Q54. Birmingham and The Black Country	149	57.7%
Q55. Derbyshire and Nottinghamshire	100	48.0%
Q56. East Anglia	92	41.3%
Q57. Essex	52	48.1%
Q58. Hertfordshire and The South Midlands	117	56.4%
Q59. Leicestershire and Lincolnshire	97	43.3%
Q60. Shropshire and Staffordshire	45	24.4%
Q64. Bath, Gloucestershire, Swindon and Wiltshire	41	31.7%
Q65. Bristol, North Somerset, Somerset and South Gloucestershire	48	62.5%
Q66. Devon, Cornwall and Isles Of Scilly	39	25.6%
Q67. Kent and Medway	46	54.3%
Q68. Surrey and Sussex	99	56.6%
Q69. Thames Valley	78	52.6%
Q70. Wessex	107	40.2%
Q71. London	408	58.3%
Scotland	176	48.9%
Northern Ireland	79	53.2%
Channel Islands	5	40.0%
Isle of Man	5	20.0%
Republic of Ireland	285	52.6%
North Wales	11	81.8%
South Wales	99	54.5%
Local Health Board unknown	8	50.0%
Hywel Dda Health Board (7A2)	11	27.3%
Abertawe Bro Morgannwg University Health Board (7A3)	22	63.6%
Cardiff and Vale University Health Board (7A4)	20	75.0%
Cwm Taf Health Board (7A5)	13	69.2%
Aneurin Bevan Health Board (7A6)	21	42.9%
Powys Teaching Health Board (7A7)	*	0.0%
Overseas	106	16.0%
Database average	**3,087**	**49.2%**
UK average	**2,686**	**50.2%**

Note: conditions used for the analysis. Fiscal Year: 2015-16; Age >=0 and <=1; Procedure Type: 1. Bypass, 2. Non-bypass, 3. Catheter, 7. Hybrid; Antenatal Diagnosis: 1. Yes, 2. No; Specific Procedures not included: ASD closure (catheter), ASD repair, PDA closure (catheter), PDA ligation (surgical), PFO closure (catheter), and Minor and Excluded Procedures.

*Numbers lower than 5

Appendix 4b: Antenatal Diagnosis 2013-16

Local Area Team (LAT)	Cases	Diagnosed antenatally (%)
England (LAT not known)	177	55.9%
Q44. Cheshire, Warrington and Wirral	128	44.5%
Q45. Durham, Darlington and Tees	179	40.2%
Q46. Greater Manchester	324	44.4%
Q47. Lancashire	175	48.6%
Q48. Merseyside	144	36.1%
Q49. Cumbria, Northumberland, Tyne and Wear	259	54.4%
Q50. North Yorkshire and Humber	169	54.4%
Q51. South Yorkshire and Bassetlaw	217	43.3%
Q52. West Yorkshire	346	39.3%
Q53. Arden, Herefordshire and Worcestershire	213	43.7%
Q54. Birmingham and The Black Country	443	53.3%
Q55. Derbyshire and Nottinghamshire	271	45.4%
Q56. East Anglia	264	45.5%
Q57. Essex	168	51.2%
Q58. Hertfordshire and The South Midlands	356	50.3%
Q59. Leicestershire and Lincolnshire	241	39.4%
Q60. Shropshire and Staffordshire	200	39.0%
Q64. Bath, Gloucestershire, Swindon and Wiltshire	122	32.8%
Q65. Bristol, North Somerset, Somerset and South Gloucestershire	148	52.7%
Q66. Devon, Cornwall and Isles Of Scilly	136	39.7%
Q67. Kent and Medway	175	56.0%
Q68. Surrey and Sussex	272	54.0%
Q69. Thames Valley	259	40.9%
Q70. Wessex	308	44.5%
Q71. London	1,273	55.8%
Scotland	496	43.1%
Northern Ireland	236	47.5%
Republic of Ireland	830	47.7%
Channel Islands	11	54.5%
Isle of Man	12	33.3%
North Wales	41	61.0%
South Wales	251	53.0%
Local Health Board unknown	23	47.8%
Hywel Dda Health Board (7A2)	29	41.4%
Abertawe Bro Morgannwg University Health Board (7A3)	43	46.5%
Cardiff and Vale University Health Board (7A4)	48	75.0%
Cwm Taf Health Board (7A5)	34	64.7%
Aneurin Bevan Health Board (7A6)	65	49.2%
Powys Teaching Health Board (7A7)	9	0.0%
Overseas	324	19.1%
Unknown	**29**	**24.1%**
Database average	**9,197**	**46.9%**

Note: conditions used for the analysis. Fiscal Year: 2013-2016; Age >=0 and <=1; Procedure Type: 1. Bypass, 2. Non-bypass, 3. Catheter, 7. Hybrid; Antenatal Diagnosis: 1. Yes, 2. No; Specific Procedures not included: ASD closure (catheter), ASD repair, PDA closure (catheter), PDA ligation (surgical), PFO closure (catheter), and Minor and Excluded Procedures.

Appendix 5: List of minor and excluded non-cardiovascular procedures

120625. Transluminal RV biopsy
122341. Transluminal intracoronary echocardiography (IVUS)
123200. Post-operative procedure
123206. Lung biopsy procedure
123214. DC cardioversion
123217. Parietal pleurectomy
123218. Post-operative procedure to control bleeding
123221. Cardiac procedure (DESCRIBE)
123228. Thoracic duct occlusion
123229. Diaphragm procedure
123240. Pericardiocentesis
123241. Pericardiocentesis – open
123243. Pericardiocentesis – transcatheter
123246. Pericardial window creation
123253. Pericardial biopsy
123259. Procedure involving pericardium (DESCRIBE)
123270. Plication of hemidiaphragm
123280. Insertion of pleural tube drain
123283. Insertion of mediastinal tube drain
123351. Peripheral vascular procedure (DESCRIBE)
123352. Non-cardiothoracic/vascular procedure (DESCRIBE)
123353. Non-cardiothoracic-vascular procedure on cardiac patient under cardiac anaesthesia
123560. Pacing to abolish arrhythmia
124000. Thoracotomy
124006. Thoracoscopic approach (VATS)
124013. Minimally invasive procedure
124099. Cardiac incision
124300. Reoperation
124325. Palliative procedure
124500. Transluminal catheter procedure
124504. Transluminal retrieval of device/foreign body
124507. Transluminal diagnostic test occlusion
124559. Transluminal procedure using adjunctive therapy
126400. Bronchoscopy
126408. Bronchoscopic removal of foreign body
126420. Tracheal procedure (DESCRIBE)
126421. Tracheostomy creation
126440. Tracheobronchial reconstruction procedure
126505. Mediastinal exploration
126506. Mediastinal procedure
126513. Pectus carinatum repair
126514. Pectus excavatum repair

126523. Anterior chest wall (pectus) repair
126545. Debridement of chest wall incision
126548. Sternal wire removal from previous sternotomy
126556. Sternotomy wound drainage
126560. Delayed closure of sternum
126572. Open excision of pleural lesion
126582. Pleurodesis
126589. Pleural procedure (DESCRIBE)
126600. Lung procedure
126601. Lung decortication
126602. Lung mass excision
126605. Lung lobectomy
126606. Pneumonectomy
126607. Lung sequestration repair
128000. Thoracic/mediastinal procedure (DESCRIBE)
128701. Cardiac support procedure
128728. Procedure involving Extracorporeal Membrane Oxygenation (ECMO) circuitry
130014. Insertable electrocardiogram (ECG) loop recorder (e.g. Reveal) implantation
130015. Insertable electrocardiogram (ECG) loop recorder (e.g. Reveal) removal
130100. Echocardiographic examination
130102. Transthoracic echocardiographic examination
130103. Transoesophageal echocardiography
130104. Epicardial echocardiographic examination
130124. Transluminal intracardiac echocardiographic examination
130127. Intravascular ultrasound (IVUS) examination

Appendix 6: List of 10 targeted major congenital heart malformations for antenatal expansion of NCHDA database

1. Hypoplastic left heart syndrome
2. Atrioventricular septal defect with normal situs
3. Atrioventricular septal defect with isomerism (heterotaxy)
4. Tetralogy of Fallot (including double outlet right ventricle variant)
5. Transposition of the great arteries with intact ventricular septum
6. Transposition of the great arteries with ventricular septal defect (including double outlet right ventricle variant)
7. Pulmonary atresia with intact ventricular septum
8. Other functionally univentricular hearts (tricuspid atresia, mitral atresia or double inlet ventricle)
9. Pulmonary atresia with ventricular septal defect
10. Common arterial trunk

In memory of David Cunningham PhD

(1954 – 2017)

As a Technical Director in 1996 David co-founded the Central Cardiac Audit Database (CCAD). The CCAD became the National Institute of Cardiovascular Outcomes Research (NICOR) in 2011 when he was appointed as a Senior Strategist until his retirement in early 2017.

After attaining a PhD in Medical Physics in 1982, David began his career in cardiac electrophysiology. He won the prestigious British Cardiac Society Young Research Workers Prize in 1984. He spent the latter years of his career making invaluable contributions to the advancement of cardiac audit and analysis. His pioneering work is reflected in what we see today in MINAP, NACRM and NACSA, and in significant contributions to the advancement of the NCHDA.