NATIONAL CONGENITAL HEART DISEASE AUDIT

2019 SUMMARY REPORT (2017/18 DATA)

NICOR

CONTENTS

BACKGROUND TO THE AUDIT

The National Congenital Heart Disease Audit (NCHDA) was set up in 2000. Originally referred to as the Central Cardiac Audit Database (congenital), it was developed to assess patient outcomes after therapeutic paediatric and congenital cardiovascular procedures (surgery, transcatheter and electrophysiological interventions) in the UK and the Republic of Ireland (since 2012). It is the largest comprehensive national audit of its kind in the world, with over 120,000 patients in the database (60% post-surgery).

Data submission is mandatory. Data are collected from all centres undertaking such procedures in children and adults.

In 2011 the audit moved from being part of the NHS Information Centre, to being one of six audits brought together under the auspices of the National Institute for Cardiovascular Outcomes Research (NICOR), and, in 2017, as a Domain within the National Cardiac Audit Programme (NCAP).

THE PURPOSE OF THE AUDIT

The purpose of the National Congenital Heart Disease Audit (NCHDA) is to examine and improve service delivery for, and outcomes of infants, children, adolescents and adults undergoing interventions for paediatric and congenital heart disease.

Patients, parents and carers, as well as clinicians and commissioners, are encouraged to review the information provided. This knowledge can then be used, together with information received from the family doctor and heart specialist, when making decisions on treatment options. Part of the audit data is also available for viewing via the website Understanding Children's Heart Surgery Outcomes, which aims to help make sense of the survival statistics provided.

The dataset for each NCAP audit broadly follows the 'clinical pathway' from admission of patients to hospital until their discharge.

The required data items are routinely reviewed to reflect the changing needs of the congenital heart services community and are designed to answer the following key questions:

- How is treatment delivered across the country, including the number of hospitals delivering services and the volume of procedures undertaken?
- Which specific procedures are provided to treat children with heart disease and congenital heart disease at any age: surgery, transcatheter interventions and electrophysiological procedures?
- What clinical outcomes are associated with these treatments and are there steps to be taken to improve on these?

ABOUT THE NCHDA

The 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 congenital cardiovascular procedures at any age, and for patients under 16 years of age with acquired heart disease who undergo interventions, as well as the success of antenatal diagnostic screening.

The NCHDA dataset is designed by clinicians working in collaboration with two professional societies: the British Congenital Cardiac Association (BCCA) and the Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS). Members of the professional societies support the NCHDA Clinical Lead, together with representation from patients, allied health professionals, and commissioners all working together with the NCAP delivery team on the NCHDA Domain Expert Group to help establish the direction of the audit programme.

1. QUALITY ASSURANCE AND QUALITY IMPROVEMENT

This report heralds a continued strong focus on identifying and communicating opportunities to raise the standards of care for patients. The NCAP uses data to help hospitals and operators drive up the quality of care, measuring processes and outcomes against achievable standards or benchmarks. This ensures that high quality services are maintained (quality assurance) but provides a means to raise the standards of care over time by identifying changes in the way care is provided (quality improvement). These changes can then be monitored to determine whether outcomes or the perceived quality of care are improved for patients or whether healthcare can be provided more efficiently.

This summary relates to the following themes:

- **Patient outcomes** – how good are the outcomes for patients and how can we improve these?
- **Safety** – how can services be made safer?
- **Clinical effectiveness** – are the best clinical protocols and treatments being used?

The specific metrics captured by the NCHDA that relate to these themes are shown in Table 1 below.

As with the aggregate NCAP report, this summary also focuses on these quality improvement themes and does not describe all the data available. The complete analyses, and audit methodology are available here.

Note: In this report the terms 'centre' and 'hospital' are used interchangeably.

2. ANALYTICAL SCOPE OF THE NATIONAL CONGENITAL HEART DISEASE AUDIT

Congenital heart disease services are a relatively small specialty accounting for just over 1% of the NHS specialised commissioning budget. Due to the relatively small number of cases involved with a large number of different procedures, the audit provides composite 3-year outcome analyses, to both allow meaningful comparison of units and minimise the risk of identifying individuals. This is in line with the Office for National Statistics (ONS) Confidentiality Guidance for publishing health statistics.

The CHD results cover 3 different time periods:

- 2017/18 data collected from April 1st 2017 - 31st March 2018, which has not been reported on in any previous report.
- 2015/16-2017/18: is the standard reporting period for metrics related to the Congenital Audit in view of relatively small numbers of individual types of procedures.
- 2007/08-2017/18: is used to demonstrate longer term trends as necessary.

2.1 | OVERVIEW OF THEMES AND METRICS

A brief description of the separate specialties that provide data for NCAP is provided in Appendix A of the 2018 NCAP main report. Appendix B of that report summarises the methodology used. The selected metrics for the Congenital Audit report are shown in Table 1 below and include a number of new metrics (in bold), reported in detail for the first time.

Table 1: *Selected metrics for the Congenital Audit with new metrics for 2015/16-2017/18 highlighted in* **bold**

Type of metric	Congenital Audit
Outcomes	30-day risk-adjusted mortality: • Aggregate 30-day mortality for all paediatric cardiac surgery procedures, risk adjusted using PRAiS2 methodology • 30-day mortality for 83 individual procedures, surgical, electrophysiological and interventional, in children and adults • **30-day risk adjusted mortality for adults (aged 16 years and older) with congenital heart disease using STAT score methodology** **Post-procedural complications in children after surgery and transcatheter interventions for congenital heart disease** **Unplanned additional procedures after surgery and transcatheter interventions for congenital heart disease**
Safety	Number of procedures (Paediatric/adult): Overall Surgical Interventional Electrophysiology (EP) **Dual operators for surgery in children** **Data Quality Index (DQI) of submitted data to NCHDA**
Effectiveness	Antenatal detection and diagnosis: • Overall in those requiring an intervention in infancy • For two specific diagnoses: hypoplastic left heart syndrome (HLHS); and transposition of the great arteries with intact ventricular septum (TGA-IVS)

3. KEY QUALITY IMPROVEMENTS FROM THE NATIONAL CONGENITAL HEART DISEASE AUDIT

3.1 | IMPROVEMENTS TO OUTCOMES

Hospitals providing care for children and adults with congenital heart disease have low levels of 30-day mortality. Survival rates remain high, and the analyses show that the observed outcomes continue to be better than those predicted (Figure 1). For the first time the Congenital Audit has used a risk model to assess outcomes in adults (aged 16 years and older) born with congenital heart disease, namely an adult congenital heart surgery mortality score derived from the Society of Thoracic Surgeons–European Association for Cardio-thoracic Surgery (STAT) mortality score used in North America and Europe.[1]

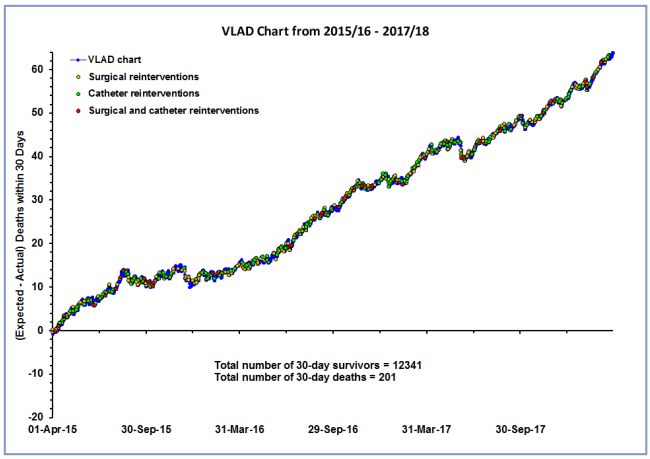
Although it is likely that these 30-day outcomes represent a true improvement in outcomes, it is important to recognise that other contributing factors may influence these outcomes. For example, the risk models may not fully account for variations in case-mix, or data collection with respect to risk factors such as non-cardiac diseases may be incomplete. Either way, the trends continue to be very encouraging.

3.1.1 30-DAY AGGREGATE SURVIVAL AFTER SURGERY IN CHILDREN

Specialist centres use Variable Life Adjusted Displays (VLAD), depicting the predicted minus the actual number of survivals at 30 days post-surgery, as well as re-interventions within 30 days of the surgery, to monitor their own outcomes. This identifies potential areas of concern or strengths, such as a 'cluster' of deaths, re-interventions, or survival of high-risk patients, thereby enabling improvements in patient safety and quality of care to be initiated. The benchmarking in the VLAD is based on the Partial Risk Adjustment in Surgery (PRAiS) model, which was revised and improved in June 2016 (PRAiS2), as well as recalibrated using the 2009/10-2015/16 Congenital Audit outcomes, with improved statistical performance.[2]

The risk model (PRAiS2) essentially benchmarks the unit's outcomes against recent national outcomes in paediatric heart surgery accounting for all the important medical aspects of case mix complexity. A positive value (line going up) following an individual patient's operation indicates improved survival in comparison with what would be predicted based on that patient's congenital heart malformation and the presence of any associated cardiac and/or non-cardiac risk factors (so-called case mix). 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. Despite this being one of the most complex areas of surgery and lifesaving for the children involved, the UK and Republic of Ireland have excellent outcomes with very low mortality rates.

Figure 1: *Variable Life Adjusted Display (VLAD) Chart for all 13 paediatric centres in the UK and Republic of Ireland undertaking procedures in patients under 16 years of age, 2015/16-2017/18*



The VLAD chart depicted in Figure 1 shows the national outcomes between 2015/16 and 2017/18, with surgical procedures represented by the blue 'VLAD chart' line, somewhat hidden by the re-intervention dots. The VLAD chart line rises continuously above the baseline, indicating that the observed 30-day outcomes during this period were better than predicted. Looking at this more closely we see that, based on the PRAiS2 risk model, 265 deaths were predicted compared to 201 actual deaths, a difference of 64 or 24% lower than the predicted number.

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 1 for types of re-intervention). To note, when VLAD charts are displayed for within centre outcome review, the number of operations included is much smaller than this (depending on programme size this would be a few hundred rather than 12,341 shown here) and therefore the individual dots are easier to discriminate visually.

These displays, therefore, enable clinical teams to identify and review clusters of re-interventions following a review of the 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 learning or quality improvement measures that can be taken forward to avoid these in future. A full interpretation of the VLAD chart can be found here.

Unadjusted raw (crude) mortality rates have also continued to fall to approximately 1.4% of 3951 surgical operations undertaken in children under 16 years of age (Figure 2) in 2017/18. Although the VLAD trend and these crude mortality rates are encouraging, it is important to note that both the risk model and assessment of life status (ONS) are based on mortality within 30 days of a surgical procedure and therefore does not account for the relatively few deaths which occurred in hospital after 30 days. These outcomes are amongst the best reported in the world, with comparable overall multicentre mortality at hospital discharge in North America in 2011-14 of 3.2% (all ages) and a derived 2014-17 rate of 2.8% (all ages).[3,4]

Figure 2: *Trends in 30 days unadjusted mortality after surgery over 10 years (2008/09-2017/18 financial years) in children (under 16 years)*

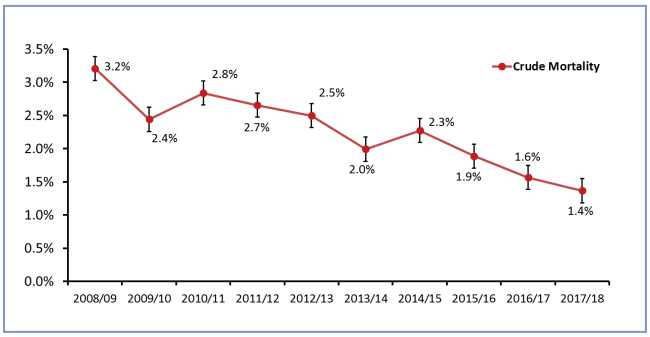
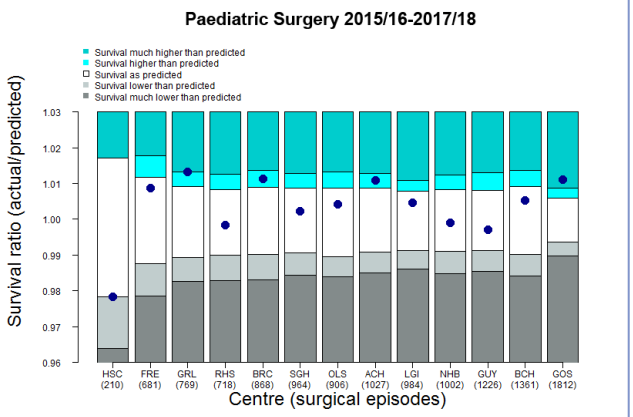


Figure 3: *Actual vs Predicted Survival Rates for all 13 centres in the UK and Republic of Ireland undertaking cardiac procedures in patients under 16 years of age 2015/16-2017/18 using PRAiS2 risk adjustment methodology*



Abbreviations: *HSC, London, Harley Street Clinic; FRE, Newcastle, Freeman Hospital; GRL, Leicester, Glenfield Hospital; RHS, Glasgow, Royal Hospital for Sick Children; BRC, Bristol Royal Hospital for Children; SGH, Southampton, Wessex Cardiothoracic Centre; OLS, Dublin, Our Lady's Children's Hospital; ACH, Liverpool, Alder Hey Children's Hospital; LGI, Leeds General Infirmary; NHB, London, Royal Brompton Hospital; GUY, London, Evelina London Children's Hospital; BCH, Birmingham Children's Hospital; GOS, London, Great Ormond Street Hospital for Children.*

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

Figure 3 shows the 30-day risk adjusted survival rates at centre level using whole program aggregated data, with risk adjustment using PRAiS2 methodology and software. Paediatric cardiac surgical procedures are defined for this analysis as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years, excluding lung transplant, extracorporeal and mechanical life support procedures and minor/non-cardiovascular procedures.

The y-axis of the figure shows the survival ratio (actual survival/predicted survival) for all units, and the x-axis the number (in parentheses) of surgical 30-day episodes. The dot represents the actual performance of a unit. The shaded bars represent the alarm and alert control limits: three standard deviations (99.5%) and two standard deviations (97.5%) respectively. For centres that fall in these zones, there is evidence (at alert level) or strong evidence (at alarm level) to suggest that survival was lower or much lower than predicted by the PRAiS2 risk adjustment model (negative outlier), or was higher or much higher than predicted (positive outlier). The performance of units falling in or above the white area, indicates survival is the same, or above, that predicted by the model. It is important to note that 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 alert limit and a 1.35% chance of being beyond the alarm limit by random chance (i.e. a false positive or negative outlier). For a more detailed, plain language explanation, see the Understanding Children's Heart Surgery website.

Table 2: *Actual and Predicted Survival Rates 2015/16-2017/18, using PRAiS2 Risk Adjustment methodology with average predicted risk per case, for all 13 units undertaking procedures in patients under 16 years of age*

Hospital	Centre Code	Surgical Episodes	Survivors	Deaths	Predicted Survival	Actual vs Predicted	Survival summary	Average predicted mortality per case
London, Harley Street Clinic	HSC	210	202	8	98.31%	0.9784	As predicted	1.69%
Newcastle, Freeman Hospital	FRE	681	669	12	97.38%	1.0088	As predicted	2.62%
Leicester, Glenfield Hospital	GRL	769	764	5	98.06%	1.0132	Higher than predicted	1.94%
Glasgow, Royal Hospital for Sick Children	RHS	718	705	13	98.35%	0.9984	As predicted	1.65%
Bristol Royal Hospital for Children	BRC	868	859	9	97.85%	1.0113	Higher than predicted	2.15%
Southampton, Wessex Cardiothoracic Centre	SGH	964	947	17	98.01%	1.0023	As predicted	1.99%
Dublin, Our Lady's Children's Hospital	OLS	906	891	15	97.93%	1.0042	As predicted	2.07%
Liverpool, Alder Hey Children's Hospital	ACH	1027	1016	11	97.87%	1.0108	Higher than predicted	2.13%
Leeds General Infirmary	LGI	984	972	12	98.32%	1.0047	As predicted	1.68%
London, Royal Brompton Hospital	NHB	1002	981	21	97.99%	0.9991	As predicted	2.01%
London, Evelina London Children's Hospital	GUY	1226	1193	33	97.59%	0.9971	As predicted	2.41%
Birmingham Children's Hospital	BCH	1361	1328	33	97.06%	1.0054	As predicted	2.94%
London, Great Ormond Street Hospital for Children	GOS	1812	1800	12	98.25%	1.0111	Much higher than predicted	1.75%

The results in Figure 3 and Table 2 show that over the last 3 years, all centres have performed such that 30-day survival was 'as predicted' or 'better than predicted', given the alert and alarm control limits, for aggregated outcomes after all surgical procedures in children. The Harley Street Clinic, which was within the negative alert level band in the 2014/15-2016/17 analyses, has now moved to be within the predicted range after improved 30-day survival in 2017/18.

Three centres performed 'better than predicted' (Alder Hey Children's Hospital, Liverpool (fourth year running); Glenfield Hospital, Leicester (second year running); and Bristol Royal Hospital for Children), whilst one centre (Great Ormond Street Hospital, London) was 'much better than predicted' for the fourth year running. This is indicative of good performance and represents an opportunity for sharing more optimal practice across specialist centres.

In addition, this year, the Congenital Audit has also calculated the average PRAiS2 risk adjusted mortality per patient operated upon at each of the 13 centres, as a way to understand the relative complexity of cases at each centre (Table 2, last column). This shows significant variance between centres (Kruskal-Wallace test, P value < 0.001), from 1.62% to 2.94%, suggesting, for instance, that the two largest centres (Birmingham Children's Hospital and Great Ormond Hospital for Children) operate upon groups of patients with significantly different risk profiles. Having said this, the PRAiS2 model should largely take these differences into account.

3.1.2 30-DAY SURVIVAL AFTER 83 SPECIFIC PROCEDURES

Survival at 30 days was analysed for 83 major surgical, transcatheter cardiovascular and electrophysiological interventions undertaken to treat congenital heart disease at any age (children and adults analysed separately), excluding minor and non-cardiovascular procedures. This is a considerable increase from the previous 57 procedures reported in 2011/12-2013/14 and the 72 procedures reported in 2013/14-2015/16. In all hospitals 30-day survival was better than the alarm (99.5%) and alert (97.5%) limits for all procedures. To see the volume of activity for specific procedures overall and procedure types, click here. This year we are unable to publish specific procedure activity numbers or 30-day outcomes as performed by individual centres with funnel plots, for data protection reasons so as to ensure anonymity of patient data where case numbers are less than three. NICOR follows the Department of Health Outlier Policy,[5] which sets out a process for providing assurance that all hospitals provide the expected quality of care. For details click here.

3.1.3 30-DAY AGGREGATE SURVIVAL AFTER SURGERY IN ADULTS

For the first time, the Congenital Audit adapted the published adult congenital heart surgery mortality score methodology, as derived from the Society of Thoracic Surgeons–European Association for Cardio-Thoracic Surgery (STAT) mortality score[1], for use as an aggregated assessment of 30-day survival for adults with congenital heart disease operated upon in the UK (currently the NCHDA do not receive adult congenital data from the Republic of Ireland). The coding system used by NCHDA and STAT system is the same (International Paediatric and Congenital Cardiac Code). The NCHDA cohort used was for all adults (16 years and older), who had undergone a surgical procedure (bypass, non-bypass & electrophysiology) in 2015/16-2017/18.

Using the STAT Specific Procedure allocation algorithm, each NCHDA surgical procedure category was allocated a STAT mortality rate, based on the post-operative outcomes of 12,513 adults with congenital heart disease (over 17 years of age, in hospital deaths) from 116 North American centres 2000/01-2012/13 within the Society of Thoracic Surgeons Congenital Heart Surgery Database here. Although mortality here is based on historical outcomes of 5-18 years ago, the 30-day mortality is known to be low in this age group and is the only published comparable data at present to base our analysis. Where the Specific Procedure category had more than one STAT mortality rate the specific cases were identified and allocated specific STAT mortality rates according to the individual case procedure code. Using this process approximately 95% of all NCHDA adult procedures were captured. Where cases were excluded, this was generally because they did not fall into one of the STAT categories or it was not possible to map the specific procedure groups to a STAT category. In the next analysis a more detailed mapping exercise will be developed using a group of clinicians to develop more sophisticated rules for inclusion and exclusion, as well as look to base these calculations on a more contemporaneous cohort of adult patients and their outcomes.

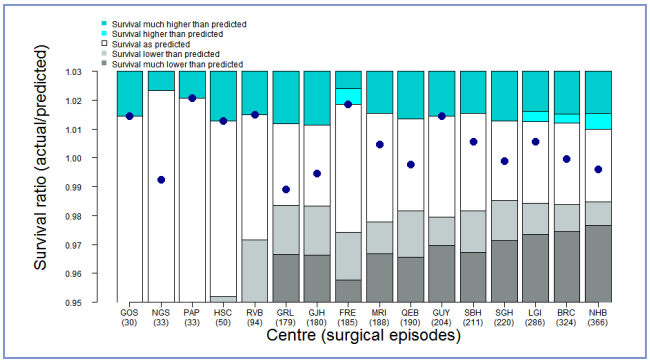
Mortality for the analysis was the usual externally validated NCHDA 30-day post-surgery outcome, as confirmed by the centre itself and the Office of National Statistics (ONS, part of NHS Digital). Cases with multiple procedures within 30 days of each other were treated in the same way as for the PRAiS methodology where the first procedure is used as the index procedure within the surgical episode. Subsequent analysis and generation of funnel plots for each centre used PRAiS2 methodology. The match of patient level data is acknowledged not to be perfect as the STAT mortality rate is based on hospital mortality (without external validation), whether before or after 30 days. Furthermore, in North America an adult is taken as over 18 years of age, whilst in NICOR the age cut off is at 16 years. However, these dissimilarities were judged to be relatively minor, and the differences between the patients themselves and congenital cardiac management strategies in North America and the UK were felt to be negligible.

The results show that there were 2,893 adult patients operated upon during 2015/16-2017/18. The overall actual to predicted mortality ratio was 0.81, approximately 19% fewer deaths than predicted by the STAT mortality model: predicted deaths were 43, whilst actual deaths were 35.

Figure 4 graphically illustrates the 30-day risk-adjusted survival rates at centre level using whole program aggregated data for adults operated upon in the UK with congenital heart disease. The y-axis of the figure shows the survival ratio (actual survival/predicted survival) for all units, and the x-axis the number (in parentheses) of surgical 30-day episodes. The dot represents the actual performance of a unit. The shaded bars represent the alarm and alert (99.5% and 97.5% respectively) control limits. The performance of units falling in or above the white area, indicates survival is the same, or above, that predicted by the STAT derived mortality rate model. The 12 centres with less than 30 procedures in the three years are not shown but are included in the overall analyses (see bottom of Table 3).

Figure 4 and Table 3 show that over the last 3 years, all 16 centres that undertook more than 30 operative procedures in 2015/16-2017/18 have performed such that 30-day survival was as predicted for aggregated outcomes after all surgical procedures in adults with congenital heart disease.

Figure 4: *Actual vs Predicted Survival Rates for the 16 centres in the UK undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over in 2015/16-2017/18 using STAT mortality score methodology*



Abbreviations: *GOS, London, Great Ormond Street Hospital for Children; NGS, Sheffield, Northern General Hospital; PAP, Cambridge, Papworth Hospital (2015/16 only); HSC, London, Harley Street Clinic; RVB, Belfast, Royal Victoria Hospital; GRL, Leicester, Glenfield Hospital; GJH, Glasgow, Golden Jubilee Hospital (only two years of data submitted: 2015/16-2016/17); FRE, Newcastle, Freeman Hospital; MRI, Manchester Royal Infirmary, QEB, Birmingham, Queen Elizabeth Hospital; GUY, London, St Thomas' Hospital and Evelina London Children's Hospital; SBH, London, University College/St Bartholomew's Hospital; SGH, Southampton, Wessex Cardiothoracic Centre; LGI, Leeds General Infirmary; BRC, Bristol Heart Institute; NHB, London, Royal Brompton Hospital.*

Note that for some centres the alert and alarm control limits coincide and for these there is therefore no 'Survival higher than predicted' band. The lower control limits are not shown for some centres as these fall outside the range of the data given that they have a low volume of patients.

Table 3: *Actual and Predicted Survival Rates 2015/16-2017/18, using STAT mortality risk methodology to give the average predicted risk of death per case for the 16 centres undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over.*

Hospital	Centre Code	Surgical Episodes	Survivors	Deaths	Actual Survival	Predicted Survival	Actual/ Predicted Survival	Average predicted mortality per case
London, Royal Brompton Hospital	NHB	366	359	7	98.09%	98.49%	0.996	1.51
Bristol Heart Institute	BRC	324	319	5	98.46%	98.50%	0.999	1.5
Leeds General Infirmary	LGI	286	283	3	98.95%	98.41%	1.006	1.59
Southampton, Wessex Cardiothoracic Centre	SGH	220	217	3	98.64%	98.74%	0.999	1.26
London, University College/St Bartholomew's Hospital	SBH	211	20*	<3	>98.5%	98.49%	>1.0	1.51
London, St Thomas' Hospital and Evelina London Children's Hospital	GUY	204	204	0	100.00%	98.58%	1.014	1.42
Birmingham, Queen Elizabeth Hospital	QEB	190	187	3	98.42%	98.66%	0.998	1.34
Manchester Royal Infirmary	MRI	188	18*	<3	>98%	98.47%	>1.0	1.53
Newcastle, Freeman Hospital	FRE	185	18*	<3	>98.3%	97.65%	>1.0	2.35

Hospital	Centre Code	Surgical Episodes	Survivors	Deaths	Actual Survival	Predicted Survival	Actual/ Predicted Survival	Average predicted mortality per case
Glasgow, Golden Jubilee Hospital †	GJH	180	177	3	98.33%	98.88%	0.994	1.12
Leicester, Glenfield Hospital	GRL	179	175	4	97.77%	98.84%	0.989	1.16
Belfast, Royal Victoria Hospital	RVB	94	94	0	100.00%	98.54%	1.015	1.46
London, Harley Street Clinic	HSC	50	50	0	100.00%	98.74%	1.013	1.26
Sheffield, Northern General Hospital	NGS	33	**	<3	>90%	97.72%	>0.9	2.28
Cambridge, Papworth Hospital (2015-16 only)	PAP	33	33	0	100.00%	97.97%	1.021	2.03
London, Great Ormond Street Hospital for Children	GOS	30	30	0	100.00%	98.58%	1.014	1.42
Other centres (12)		120	11*	<3	>97%	98.40%	>1.0	1.6
Overall		**2893**	**2858**	**35**	**98.79%**	**98.50%**	**1.003**	**1.5**

† Note: Glasgow, Golden Jubilee Hospital submitted only two years of data: 2015/16-2016/17

Note: All centres performed 'as predicted' with no negative or positive outliers.

*N.B. Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable. An * represents a digit between 0 and 9. For example, 20* could be read as an integer between 200 and 209. Percentages have been adjusted accordingly. This process was conducted for data protection reasons, to ensure anonymity of the patient data included in reporting.*

Whilst all these 30-day post-procedure outcomes continue to be very reassuring for patients and families, as well as other stakeholders such as commissioners, it must underpin a commitment to move beyond 30-day survival rates and to explore methods to assess longer term survival, and other outcome measures (e.g. the incidence of post-procedural complications or quality of life in survivors). From April 2015 the Congenital Audit dataset was updated to support these goals with several additional fields: post-operative and post-interventional procedure complications and documenting if additional procedures are expected or unexpected with respect to the individual patient's care management pathway. Data and first-time analyses using these new fields are reported below.

3.1.4 POST-PROCEDURAL COMPLICATIONS

Given the current excellent early survival rates for paediatric and congenital heart interventions, there has been agreement for some time by all stakeholders that this important safety outcome should be supplemented by a wider range of outcome measures. A recent 5 centre UK based study was undertaken to prospectively measure the incidence of complications (also termed morbidities) following paediatric cardiac surgery and to evaluate the clinical and health-economic impact over the 6-months following surgery in 2015/16-2017/18. Clinicians involved included members of the NCHDA Domain Expert Group. Within this study, families and clinicians prioritised the following as principle post-operative events to monitor and define: acute neurological event, unplanned re-intervention, feeding problems, renal replacement therapy, major adverse events, the need for extracorporeal life support, necrotising enterocolitis, post-surgical site infection, and prolonged pleural effusion or chylothorax.[6] Amongst 3,090 consecutive cardiac operations there were 675 (21.8%) with at least one of these morbidities. Independent significant risk factors for morbidity included neonatal age, complex heart disease and prolonged cardiopulmonary bypass, whilst 6 months survival was less when morbidities were documented (88·2% compared to 99·3%) without a morbidity.[7]

Parallel to this study, in April 2015 the NCHDA introduced separate data fields to capture post-procedural complications following surgery and transcatheter interventions (including electrophysiology), in anticipation of being able to analyse three years of data during the current analytical cycle. For the purposes of the Congenital Audit a complication is defined as an event or occurrence that is associated with a disease or a healthcare intervention, which is a departure from the desired course of events, and may cause, or be associated with, suboptimal outcome.

A complication does not necessarily represent a breach in the standard of care that constitutes medical negligence or medical malpractice. A procedure related complication is any complication, regardless of cause, occurring within 30 days after surgery or intervention in or out of the hospital. Procedural complications include both intra-procedural and post-procedural complications in this time interval.[8] For full definitions of complications analysed in this cycle, see Appendix 1.

30-day procedure related complication rates for children (less than 16 years of age) following 13,009 surgical procedures and 8,655 transcatheter interventions at 12 UK and Republic of Ireland centres during 2015/18 are reported. This is the first time the Congenital Audit has run and reported these analyses. There are two important reasons why the data should be interpreted with caution and regarded as somewhat preliminary this year. The first is the lack of a valid method of case mix adjustment for complications data, in a setting where there are reported differences in case mix between centres (see Table 2, page 6). The second is the variable data quality for complications data, which was especially variable for adult patients. Further, one private paediatric centre, the Harley Street Clinic, was also excluded because their submission did not contain any data on post-operative complications, which must reflect poor data quality in this respect. All other centres submitted complication data and an assumption was made on this occasion for these centres that when these fields were blank, that no complication occurred (a small minority of cases at nearly all centres). This work is therefore at a preliminary stage and the validity of some of these fields requires further clarification to ensure centres are reporting similar endpoints. Consequently, some fields with more definable endpoints are of more significance than others. Data quality in fields with less hard endpoints will in future be a priority, as described for 'Unplanned re-operations' (next section).

The analyses focussed on 5 surgical and 2 interventional catheter related complications. The data quality for catheter related local complications, usually involving femoral arterial access, was too variable or missing at centre level to currently merit reporting.

The main findings were:

Acute surgery related neurological event. Overall there were <160 patients affected with a low overall rate of 1.2% (range per centre <0.35-2.75%): neonatal 2% (4*/2467), infant 1.2% (6*/5400), child 0.9% (45/5142). Results per centre are shown in Table 4, but it is important to be aware of the broad range of possible events under this definition before trying to draw conclusions with respect to the variance seen (seizures to strokes). Such an event occurred most frequently following a Norwood procedure (e.g. for hypoplastic left heart syndrome) at 4.9% (14/284), following heart transplantation at 3.8% (4/105) and following repair of complex transposition of the great arteries with or without arch repair at 3.8% (4/106). For this particular complication, we note that the focus is relatively narrow in scope and that children undergoing heart surgery may have neuro-developmental problems for a range of reasons, including congenital syndromic conditions, unrelated to heart surgery. These and the fact that more subtle neurological manifestations may not become apparent until many months after the procedure are not covered by this audit.

Table 4: *Incidence of surgery related acute neurological event in children (under 16 years of age) at the 12 UK and Republic of Ireland centres.*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1428	23	1451	1.59%
Bristol Royal Hospital for Children	BRC	92*	<3	928	<0.35%
Dublin, Our Lady's Children's Hospital	OLS	945	11	956	1.15%
Glasgow, Royal Hospital for Sick Children	RHS	743	21	764	2.75%
Leeds General Infirmary	LGI	1018	4	1022	0.39%
Leicester, Glenfield Hospital	GRL	817	4	821	0.49%
Liverpool, Alder Hey Children's Hospital	ACH	1073	6	1079	0.56%
London, Evelina Children's Hospital	GUY	1244	29	1273	2.28%
London, Great Ormond Street Hospital for Children	GOS	1899	30	1929	1.56%
London, Royal Brompton Hospital	NHB	1026	15	1041	1.44%
Newcastle - Freeman Hospital	FRE	739	3	742	0.40%
Southampton University Hospital	SGH	995	8	1003	0.80%
Total		**1285***	**15***	**13009**	**1.20%**

*N.B. Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable. An * represents a digit between 0 and 9. For example, 20* could be read as an integer between 200 and 209. Percentages have been adjusted accordingly. This process was conducted for data protection reasons, to ensure anonymity of the patient data included in reporting.*

Post-surgical use of extracorporeal life support (ECMO). The overall rate of this important and impactful adverse event was 2.2% (range per centre 1.0-4.7%): neonatal 4.9% (120/2467), infant 1.8% (98/5400), child 1.2% (63/5142). There is some centre-related variability with highest rates in Glasgow (4.7%) and those with a national ECMO program (Newcastle, Leicester; 3.5-3.6%), as shown in Table 5. This may reflect a lower threshold for resorting to mechanical support following surgery. Post-operative ECMO is also well known to vary in usage based on procedure type as has been shown in the STS Registry,[9] as was evident in the NCHDA data. Highest post-operative ECMO rates were following heart transplantation at 18.1% (19/105), a Norwood procedure at 13% (37/284), repair of common arterial trunk at 10.6% (7/66), repair of anomalous coronary artery at 9.8% (6/61) and complex transposition of great arteries with or without arch repair (9.2% (10/109).

Table 5: *Incidence of post-surgical use of extracorporeal life support in children (under 16 years of age) at the 12 UK and Republic of Ireland centres.*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1432	19	1451	1.31%
Bristol Royal Hospital for Children	BRC	913	15	928	1.62%
Dublin, Our Lady's Children's Hospital	OLS	939	17	956	1.78%
Glasgow, Royal Hospital for Sick Children	RHS	728	36	764	4.71%
Leeds General Infirmary	LGI	1008	14	1022	1.37%
Leicester, Glenfield Hospital	GRL	792	29	821	3.53%
Liverpool, Alder Hey Children's Hospital	ACH	1053	26	1079	2.41%
London, Evelina Children's Hospital	GUY	1253	20	1273	1.57%
London, Great Ormond Street Hospital for Children	GOS	1887	42	1929	2.18%
London, Royal Brompton Hospital	NHB	1015	26	1041	2.50%
Newcastle - Freeman Hospital	FRE	715	27	742	3.64%
Southampton University Hospital	SGH	993	10	1003	1.00%
Total		**12728**	**281**	**13009**	**2.16%**

Incidence of post-surgical renal replacement therapy (dialysis). The overall rate was 3.3% (range per centre 1.0-6.5%): neonatal 8.7% (215/2467), infant 2.4% (129/5400), child 1.6% (84/5142). There is considerable inter-centre variability from under 1.5% (Dublin, Leicester, Birmingham) to 5-7% (Great Ormond Street, Glasgow, Bristol), as shown in Table 6. This most likely reflects differing intensive care management practices with some units using high dose diuretic therapy compared to others with a lower threshold for instigating dialysis. Further analysis with respect to length of stay and time to extubation is warranted to examine if there is a material difference in outcomes between centres using different strategies. The use of dialysis occurred most frequently following operative repair of complex transposition with or without arch repair at 17.4% (19/109), with repair of common arterial trunk (11/66), Norwood procedure (46/284), heart transplant (17/105) all at around 16%, and repair of transposition with ventricular septal defect (18/144) and total anomalous pulmonary venous connection repair (20/173) at around 12%.

Table 6: *Incidence of post-surgical use of renal replacement therapy (dialysis) in children (under 16 years of age) at the 12 UK and Republic of Ireland centres.*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1433	18	1451	1.24%
Bristol Royal Hospital for Children	BRC	868	60	928	6.47%
Dublin, Our Lady's Children's Hospital	OLS	948	8	956	0.84%
Glasgow, Royal Hospital for Sick Children	RHS	721	43	764	5.63%
Leeds General Infirmary	LGI	1006	16	1022	1.57%
Leicester, Glenfield Hospital	GRL	813	8	821	0.97%
Liverpool, Alder Hey Children's Hospital	ACH	1029	50	1079	4.63%
London, Evelina Children's Hospital	GUY	1224	49	1273	3.85%
London, Great Ormond Street Hospital for Children	GOS	1833	96	1929	4.98%
London, Royal Brompton Hospital	NHB	1009	32	1041	3.07%
Newcastle - Freeman Hospital	FRE	717	25	742	3.37%
Southampton University Hospital	SGH	980	23	1003	2.29%
Total		**12581**	**428**	**13009**	**3.29%**

Post-surgical requirement for a pacemaker (unplanned). Overall there were 130 cases with a somewhat reassuringly low rate of 1.0% (range per centre 0.5-2.3%): neonatal 0.4% (11/2467), infant 0.9% (48/5400), child 1.4% (71/5142). There was some inter-centre variability (Table 7), requiring more detailed case by case review, given that certain procedures are expected to be at much higher risk for this complication, such as left ventricular outflow tract surgery. Most frequent procedures were mitral valve replacement at 6.5% (7/107), tetralogy of Fallot with atrioventricular septal defect repair at 5.3% (2/38) and surgery inclusive of a procedure involving the left ventricular outflow tract at 3.2% (19/594).

Table 7: *Incidence for the unplanned placement of a pacemaker following congenital cardiac surgery in children (under 16 years of age) at the 12 UK and Republic of Ireland centres.*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1431	20	1451	1.38%
Bristol Royal Hospital for Children	BRC	907	21	928	2.26%
Dublin, Our Lady's Children's Hospital	OLS	951	5	956	0.52%
Glasgow, Royal Hospital for Sick Children	RHS	753	11	764	1.44%
Leeds General Infirmary	LGI	1016	6	1022	0.59%
Leicester, Glenfield Hospital	GRL	814	7	821	0.85%
Liverpool, Alder Hey Children's Hospital	ACH	1072	7	1079	0.65%
London, Evelina Children's Hospital	GUY	1266	7	1273	0.55%
London, Great Ormond Street Hospital for Children	GOS	1910	19	1929	0.98%
London, Royal Brompton Hospital	NHB	1030	11	1041	1.06%
Newcastle - Freeman Hospital	FRE	737	5	742	0.67%
Southampton University Hospital	SGH	992	11	1003	1.10%
Total		**12879**	**130**	**13009**	**1.00%**

Post-surgical requirement for prolonged pleural drainage (greater than 7-10 days). Overall there were <580 cases with a rate of 4.4% (range per centre <0.4-12.6%): neonatal 4.3% (10*/2467), infant 3.1% (16*/5400), child 5.9% (302/5142). There were clear differences between centres with highest rates at Glasgow (12.6%) and Birmingham (10.7%), as shown in Table 8, requiring more detailed case by case review, given that certain procedures are expected to be at much higher risk for this complication, such as Fontan-type procedures. As of this year the Congenital Audit is changing the definition to be beyond 10 days of drainage to be in line with the definitions used by the national Congenital Heart Services Quality Dashboard.

Table 8: *Incidence of prolonged pleural drainage (over 7-10 days) following congenital cardiac surgery in children (under 16 years of age) at the 12 UK and Republic of Ireland centres.*

Hospital		No	Yes	Total	%
Birmingham Children's Hospital	BCH	1295	156	1451	10.75%
Bristol Royal Hospital for Children	BRC	890	38	928	4.09%
Dublin, Our Lady's Children's Hospital	OLS	909	47	956	4.92%
Glasgow, Royal Hospital for Sick Children	RHS	668	96	764	12.57%
Leeds General Infirmary	LGI	1014	8	1022	0.78%
Leicester, Glenfield Hospital	GRL	81*	<3	821	<0.4%
Liverpool, Alder Hey Children's Hospital	ACH	1053	26	1079	2.41%
London, Evelina Children's Hospital	GUY	1239	34	1273	2.67%
London, Great Ormond Street Hospital for Children	GOS	1840	89	1929	4.61%
London, Royal Brompton Hospital	NHB	1014	27	1041	2.59%
Newcastle - Freeman Hospital	FRE	734	8	742	1.08%
Southampton University Hospital	SGH	959	44	1003	4.39%
Total		**1243***	**57***	**13009**	**4.42%**

*N.B. Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable. An * represents a digit between 0 and 9. For example, 20* could be read as an integer between 200 and 209. Percentages have been adjusted accordingly. This process was conducted for data protection reasons, to ensure anonymity of the patient data included in reporting.*

Catheter procedure requirement for emergency complication-related procedure (surgery or transcatheter). Overall there were 64 cases with a reassuringly low rate of 0.7% (range per centre <0.6-1.6%): neonatal 2.4% (23/937), infant 0.8% (15/1766), child 0.4% (26/5952). There was some centre level variability (0.2-1.6%) possibly reflecting case complexity (Table 9). Most frequent procedures were not surprisingly neonatal radiofrequency pulmonary valve perforation-dilation (3 of 34 cases, 8.8%) and stent placement in the right ventricular outflow tract (9 of 205 cases, 4.4%), as both procedures may involve inadvertent perforation of the right ventricular or pulmonary outflow tracts.

Table 9: *Incidence of the need for an emergency complication related procedure (surgery or transcatheter) related to a transcatheter procedure in children (under 16 years of age) at the 12 UK and Republic of Ireland centres.*

Hospital		No	Yes	Total	%
Birmingham Children's Hospital	BCH	1020	5	1025	0.49%
Bristol Royal Hospital for Children	BRC	597	6	603	1.00%
Dublin, Our Lady's Children's Hospital	OLS	1223	5	1228	0.41%
Glasgow, Royal Hospital for Sick Children	RHS	47*	<3	476	<0.7%
Leeds General Infirmary	LGI	837	4	841	0.48%
Leicester, Glenfield Hospital	GRL	39*	<3	396	<0.8%
Liverpool, Alder Hey Children's Hospital	ACH	651	6	657	0.91%
London, Evelina Children's Hospital	GUY	548	6	554	1.08%
London, Great Ormond Street Hospital for Children	GOS	812	13	825	1.58%
London, Royal Brompton Hospital	NHB	1007	9	1016	0.89%
Newcastle - Freeman Hospital	FRE	50*	<3	511	<0.6%
Southampton University Hospital	SGH	518	5	523	0.96%
Total		**8591**	**64**	**8655**	**0.74%**

*N.B. Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable. An * represents a digit between 0 and 9. For example, 20* could be read as an integer between 200 and 209. Percentages have been adjusted accordingly. This process was conducted for data protection reasons, to ensure anonymity of the patient data included in reporting.*

Catheter-related device embolisation. Overall there were 55 cases with a reassuringly low rate of 0.6% (range per centre <0.4-1.6%): neonatal 1.4% (13/937), infant 0.6% (11/1766), child 0.1% (5/5952). There was some inter-centre variability (<0.4-1.6%) likely reflecting case complexity (Table 10). Procedures where this was seen most frequently included transcatheter ventricular septal defect closure at 2.9% (3/104), pulmonary arterial stent placement at 1.8% (7/399) and patent arterial duct closure at 1.4% (23/1649).

Table 10: *Incidence of catheter-related device embolisation following or during a transcatheter procedure in children (under 16 years of age) at the 12 UK and Republic of Ireland centres.*

Hospital		No	Yes	Total	%
Birmingham Children's Hospital	BCH	1016	9	1025	0.88%
Bristol Royal Hospital for Children	BRC	6**	<3	603	<0.5%
Dublin, Our Lady's Children's Hospital	OLS	1224	4	1228	0.33%
Glasgow, Royal Hospital for Sick Children	RHS	47*	6	476	1.26%
Leeds General Infirmary	LGI	83*	<3	841	<0.4%
Leicester, Glenfield Hospital	GRL	39*	<3	396	<0.8%
Liverpool, Alder Hey Children's Hospital	ACH	651	6	657	0.91%
London, Evelina Children's Hospital	GUY	550	4	554	0.72%
London, Great Ormond Street Hospital for Children	GOS	82*	<3	825	<0.4%
London, Royal Brompton Hospital	NHB	1000	16	1016	1.57%
Newcastle - Freeman Hospital	FRE	5**	<3	511	<0.6%
Southampton University Hospital	SGH	5**	<3	523	<0.6%
Total		**8600**	**55**	**8655**	**0.64%**

*N.B. Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable. An * represents a digit between 0 and 9. For example, 20* could be read as an integer between 200 and 209. Percentages have been adjusted accordingly. This process was conducted for data protection reasons, to ensure anonymity of the patient data included in reporting.*

Evaluation of post-operative morbidity is more complicated than measuring early mortality. However, documenting these complications after paediatric cardiac surgery offers important data that are of value to parents, the clinicians at the centres undertaking the operations and specialist commissioners, and will likely be useful in driving future quality improvement. The current set of measures is therefore the first step in this pathway. The overall incidence of these complications is already submitted quarterly by each centre undertaking congenital heart procedures as part of the Specialist Services Quality Dashboard, with scrutiny by the congenital heart services Clinical Reference Group. However, these submissions by the centres do not include individual complications as published here, making it difficult to understand or consider variability between centres. As next steps, the Congenital Audit intends to drill down on each metric as appropriate, endeavouring to understand inter-centre variability, including discussions with the audit leads at the congenital heart

centres. In addition, case level investigations may be helpful to understand and learn from, for example, why there remains an incidence of post-operative complete heart block requiring a pacemaker due to damage to the conduction system after certain operations.

3.1.5 UNPLANNED RE-OPERATIONS

In April 2015 the NCHDA introduced the data field of 'Unplanned re-operation' to be coded 'Yes/No' for each procedure undertaken, as well as 'Procedure urgency' (elective, urgent, emergency, salvage) as an additional way to understand re-interventions that may have occurred. This was in anticipation of being able to analyse three years of data during the current analytical cycle.

Unplanned re-operations are defined for the purposes of the Congenital Audit as procedures outside the expected planned patient pathway which may be undertaken at any time from the start of the post-procedural ward admission up until 30 days following the primary procedure.[6] Staged procedures are not counted as re-operations as they are planned and expected, such as when a balloon atrial septostomy is followed by an arterial switch procedure for transposition of the great arteries. Additional procedures or revisions undertaken during the primary operation in the operating theatre are not included, such as return to cardiopulmonary bypass when an echocardiographic assessment suggests a suboptimal result at that stage.

An example of an unplanned re-operation would be where a closure device for an atrial septal defect migrated from its implanted position to another part of the cardiovascular system and required urgent surgical device removal. Unplanned re-operations may be cardiac bypass, non-bypass, pacemaker placement (lead revision/repositioning), interventional catheterisations or diaphragm plication. The definition does not include procedures for post-procedural bleeding, closure of chest, cardiopulmonary life support when classified as a complication (e.g. ventricular assist device or extracorporeal membranous oxygenation (ECMO)) or other non-cardiac or cardiac surgical procedures that would be classified in the 'Minor and Excluded Procedures' procedure type, irrespective of the urgency.

The data were examined for the first time using submitted 2015/18 data and unfortunately revealed significant data quality issues. Of 38,212 cases with valid procedure coding, missing 'unplanned re-operation' status was found in 730 cases (1.9%) but varying from 0% to 100% at some centres. Furthermore, there appeared to be clear areas of concern with respect to the coding itself, such as a valve repair followed by valve replacement within 30 days not being classified as an unplanned procedure. In addition, the correlation with 'procedure urgency' was difficult to understand with 426 unplanned procedures being classified as elective – this may be the case but seems unlikely.

For these reasons no further analysis was undertaken this year in this area, whilst data quality issues are addressed with each centre. There was insufficient time to do this within the current analytical cycle. Each centre will be sent a listing of questionable cases found over the last three years of data submission, for review and recoding if found to be inaccurate. Missing data will also be filled retrospectively.

Going forward, a new data completeness tool will be implemented, which will include these fields, as well as identifying specific concerns where data are considered to be inconsistent or invalid. The expectation is that these will be corrected or confirmed within the following 2-3 months before the next quarterly summary is sent. In this way we anticipate being able to perform a more meaningful analysis of unplanned re-operations with inter-centre comparisons in the next analytical cycle which is planned to include data from 2015/16-2018/19.

3.2 IMPROVEMENTS TO SAFETY

The volume of procedures carried out can be a significant factor in developing the necessary skills and infrastructure for treating patients with congenital cardiac malformations. As with the other audits, it is generally accepted that performance improves the more one practices a specific skill – 'practice makes perfect' – and professional societies, regulators and commissioners have recommended certain minimum volumes of activity at hospitals for particular services, including congenital heart disease. As detailed below, for congenital heart interventions this has hinged upon minimum volumes of activity for individual operators at 125 cases minimum per surgeon averaged over 3 years, along with a minimum of a 1 in 3 on call rota (ideally at least 1 in 4).[10]

There remains no objective data to show the effect of implementing these recommendations across the country with respect to outcomes, but the expectation is that higher volumes will deliver a more consistent and sustainable service with the appropriate infrastructure to treat these complex patients born with a huge variety of cardiac malformations.

Previous analysis of the Congenital Audit data was not able to identify a statistically-significant volume-outcomes relationship for UK centres undertaking paediatric cardiac procedures, although there was a definite trend to support better outcomes in larger centres. This supports the way that congenital heart centres have been commissioned in the UK over the last decade, not allowing NHS centre volumes to fall to the low numbers that can occur in other countries (including the USA).

3.2.1 ALL PAEDIATRIC AND CONGENITAL HEART PROCEDURES

In 2017/18, UK and Republic of Ireland centres submitted data on 12,247 procedures where 8780 were paediatric cases and 3467 were adult congenital heart cases. A full breakdown of 30 day outcomes by age group for all procedures (2015/16-2017/18) is available on the NCHDA website.

Table 11: *Total number of cases categorised by type of procedure submitted to the NCHDA in financial years 2003/04 - 2017/18*

Year	Surgical	Hybrid	Catheter			Diagnostic Catheter	Total
			Interventional	EP/Pacing	ICD		
2003-04	4497	0		2928		—	7425
2004-05	4346	0		3032		—	7378
2005-06	4638	3		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
2016-17	5642	48	3837	1459	154	1879	13019
2017-18	**5292**	**78**	**3680**	**1397**	**108**	**1692**	**12247**

Note: Primary Extracorporeal Membranous Oxygenation (ECMO), Ventricular Assist Devices (VAD) and lung transplants are counted as surgical activity for these calculations; interventional, Electrophysiology (EP)/Pacing and Implantable cardioverter-defibrillator (ICD) devices are counted as catheter procedures, not collated separately until 2013/14 financial year. Hybrid procedures are those with a combination of surgical and transluminal catheter interventions undertaken at the same time in the operating theatre. Diagnostic catheter data were included in the dataset from 2015/16 onwards.

Figure 5: *Surgical and catheter-based procedures submitted to the NCHDA in financial years 2015/6-2017/18, excluding diagnostic catheters.*

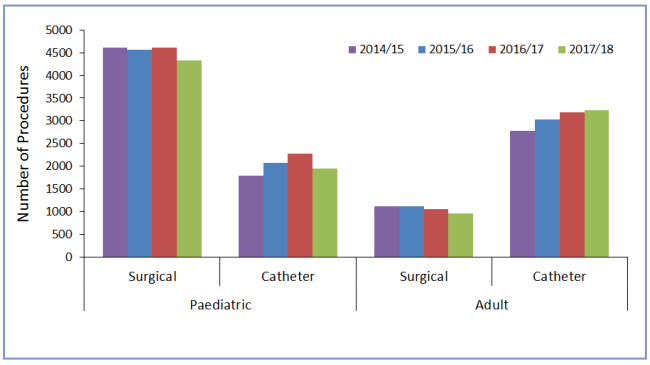


Table 11 and Figure 5 show that surgical activity over the last four years has slightly fallen in the UK and Republic of Ireland, with a 6% reduction in paediatric activity in 2017/18. An initial increase in transcatheter and electrophysiological activity in the same time period, as an aggregate, was also followed by a similar reduction of 5% in 2017/18 in children but a continued slight rise in transcatheter procedures in those 16 years and older. Further work is required to see if these figures correspond to a change in management strategies for individual lesions, such as an increase in transcatheter pulmonary valve implants in adults as an alternative to a surgical approach.

3.2.2 NATIONAL STANDARDS AND CONSULTANT ACTIVITY

The NHS England national standards for manpower, related procedural volume and infrastructure are based on the expectation that this will ensure a consistent and sustainable service to help continue to improve the outcomes for paediatric and congenital heart patients of all ages.[4] A key NHS England Standard is that consultant congenital heart surgeons are expected to undertake a minimum of 125 congenital or paediatric cardiovascular operations on patients of any age each year (averaged over a three-year period); whilst for catheter interventions it is 50 procedures each and 100 for the lead interventionist (noting that for the lead interventionist this can

include dual scrubbing with a consultant colleague).[11] However, an area that remains controversial when calculating the number of procedures an individual consultant operator undertakes, is the scenario when there are two consultants scrubbed for the same patient (excluding a consultant scrubbing with a non-consultant trainee). For the first time the Congenital Audit has calculated these numbers, as shown in Table 12 and Figures 6-7.

Table 12: *Total number of cases submitted to the NCHDA categorised by type of procedure and age group in 2015/16-2017/18 (financial years), illustrating the number of cases with two consultants operating at the same session.*

Hospital	All ages – dual/total		Neonates		Infant		Child		Adult	
Surgery (overall)	**1,887/16,812**	**11%**	**421/2622**	**16%**	**536/5613**	**10%**	**606/5447**	**11%**	**324/3130**	**10%**
Bypass	1,587/13,203	12%	330/1559	21%	431/4167	10%	528/4555	12%	298/2922	10%
Non-bypass	146/3,165	5%	51/915	6%	50/1345	4%	30/718	4%	15/187	8%
Hybrid	127/181	70%	38/59	64%	49/67	73%	31/42	74%	9/13	69%
Primary ECMO	8/191	4%	1/88	1%	4/27	15%	3/73	4%	0/3	0%
Ventricular Assist Device (VAD)	19/72	26%	1/1	100%	2/7	29%	14/59	24%	2/5	40%
Catheter/Electrophysiology (overall)	**4,257/21,044**	**20%**	**290/1087**	**27%**	**519/2660**	**20%**	**1453/9204**	**16%**	**1995/8093**	**25%**
Interventional	2,980/11,151	27%	261/936	28%	412/1758	23%	841/4640	18%	1466/3817	38%
Implantable Cardioverter Defibrillator(ICD)	43/387	11%	0/0	0%	1/2	50%	20/112	18%	22/273	8%
Pacemaker procedures	100/1,181	8%	0/1	0%	1/9	11%	48/390	12%	51/781	7%
EP & ablation & diagnostic EP	523/3,019	17%	0/1	0%	2/8	25%	329/1582	21%	192/1428	13%
Diagnostic catheter	611/5,306	12%	29/149)	20%	103/883	12%	215/2480	9%	264/1794	15%

Figure 6: *Bar chart showing the percentage of patients of any age who had their procedure undertaken by two consultant operators, broken down by procedure type in 2015/16-2017/18 (financial years)*

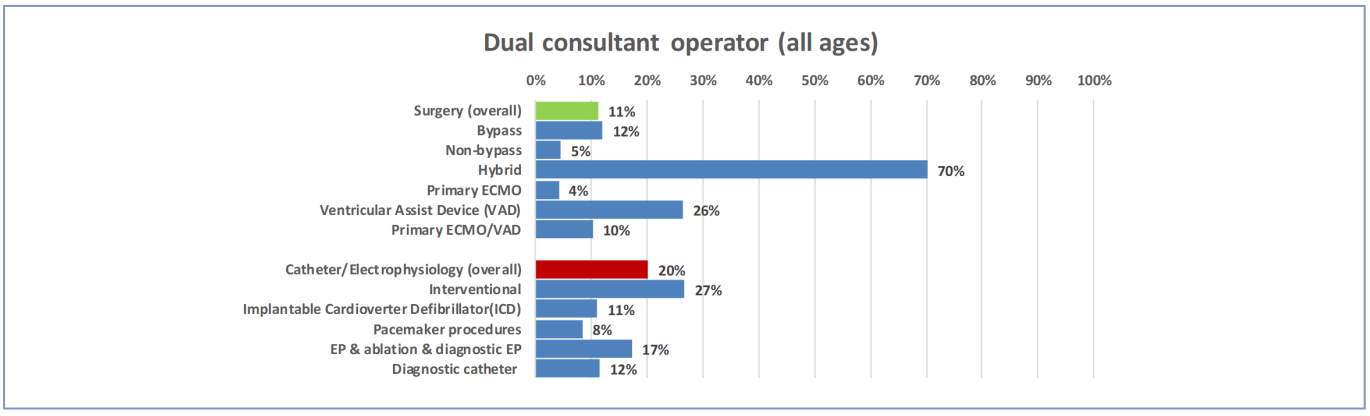
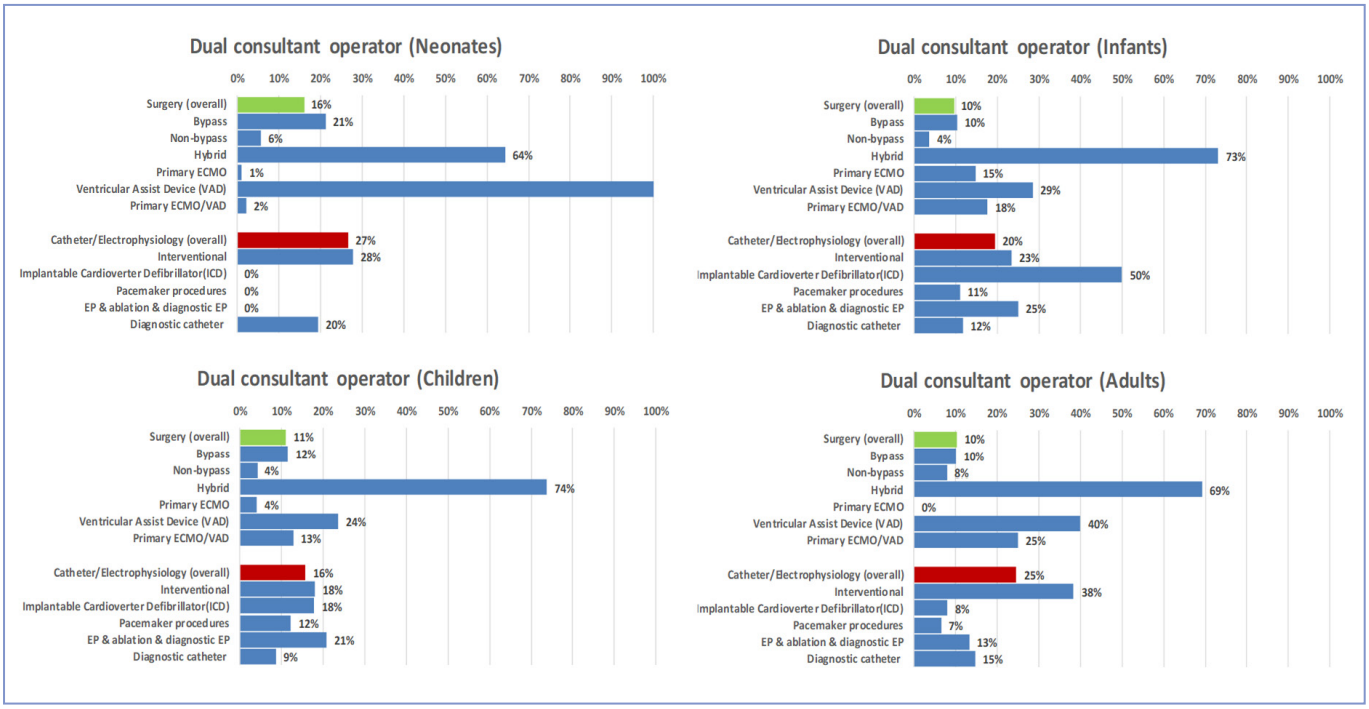


Figure 7: *Bar charts showing the percentage of patients who had their procedure undertaken by two consultant operators, broken down by procedure type and age bracket in 2015/16-2017/18 (financial years)*



For 2015/16-2017/18, the dual consultant operator data show that over a fifth of all neonatal surgical and over a quarter of neonatal transcatheter interventions were undertaken by two consultant operators, whilst this is the case in 10% of older children and adults having surgery. In contrast, over a third of transcatheter interventions in adults have dual consultant operators, probably attributable to the number of transcatheter valve implants undertaken. There are three scenarios when dual consultant operators are likely to be scrubbed for a procedure:

- Planned: due to the case being a hybrid procedure with required input by both a consultant surgeon and consultant catheter interventionist; or due to case or procedure complexity, such as atypical coronary anatomy when undertaking an arterial switch procedure, or with transcatheter valve implantation

- Planned: when mentoring/training a junior consultant colleague or teaching a new technique

- Unplanned: when there is an unexpected intra-operative finding or complication.

To better understand prospectively the reasons for dual consultant operators, for which procedures and for which centres, the NCHDA dataset has been expanded for the 2019/20 cycle to include these three sub-categories in this data field.

The NHS England review concluded that not all English centres treating children and adults fully met the current requirements. Hospitals undertaking congenital cardiac surgery should continue to work with specialist commissioners and aim to meet the NHS England Standards[11], which will be reviewed again in three years' time.

Volume of activity is not the only consideration for good outcomes and there are other issues to consider. These include the sustainability of services, the numbers of support staff, the infrastructure needed and the frequency of on-call commitments. To better understand these factors within a quality assurance and improvement framework, the NHS England Quality Surveillance Team with senior congenital heart clinicians is undertaking peer review visits to all centres involved in tertiary level congenital heart services for children in England, Scotland and Wales during 2019.

A series of Qualitative Indicators have been developed to assess compliance with the congenital heart service standards[11], focussing on key areas of infrastructure and process that are indicative and relevant to delivering a robust and sustainable service, and that support improved clinical and patient reported outcomes. These centre reviews should identify potential causes of variation in outcomes, which may be important for optimising the standard of care for those undergoing congenital heart procedures, providing an opportunity for sharing good practice across specialist centres as well as learning from centres with sustained better than predicted outcomes (see above).

3.3 IMPROVEMENTS TO CLINICAL EFFECTIVENESS

3.3.1 ANTENATAL DIAGNOSIS

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.[12] 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. Poor antenatal diagnosis rates are associated with limited opportunity to counsel expectant patients and worse outcomes for babies.[13] We do not yet know what proportion of children with CHD are diagnosed antenatally (NICOR is working with Public Health England to develop better measures) but we do know this for those children who have a procedure in the first year of life. Amongst this group, detection continues to improve with over half of these children currently diagnosed before birth.

Although at present there are no agreed international standards, the current aims of the Congenital Audit along with the National Fetal Cardiology Group are:

- To achieve an antenatal diagnosis rate of at least 75% for all abnormalities where an intervention is undertaken in the first year of life; and
- To achieve an antenatal diagnostic rate of at least 90% for two specific illustrative abnormalities, namely hypoplastic left heart syndrome (HLHS) as a type of functionally univentricular heart, and transposition of the great arteries with intact ventricular septum (TGA-IVS), as an example of a major malformation of the great arteries.

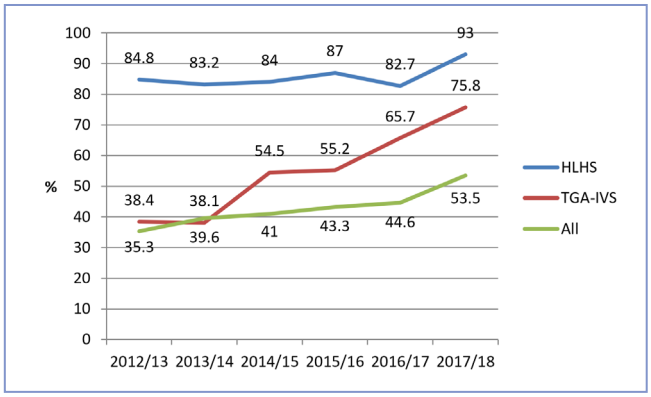
Antenatal diagnoses require sophisticated ultrasonography equipment and highly skilled obstetric sonographers to acquire and interpret the images. Fetal cardiac screening is undertaken as part of the maternity service provided by local hospitals, and not at specialist congenital heart centres. A robust and swift referral system to fetal cardiologists is therefore also required, following the finding of a possible fetal heart anomaly. A definitive diagnosis can then be made and a management pathway for the pregnancy agreed, along with appropriate counselling and support for the parents and the coordination of postnatal care.[14] The latest audit data for 2017/18 show a continuing positive trend in antenatal detection rates of all infants requiring a procedure in infancy (Table 13 and Figure 8).

Table 13: *Proportion of patients undergoing procedures in infancy successfully diagnosed antenatally (financial years 2008/09 to 2017/18) in the UK and Republic of Ireland.*

Year	Overall diagnosis	% Antenatally diagnosed
2008	1828	28.8%
2009	2156	29.8%
2010	2185	32.4%
2011	2204	35.0%
2012	2217	35.3%
2013	2168	39.6%
2014	2136	41.0%
2015	2241	43.3%
2016	2147	44.6%
2017	**1590**	**53.5%**

Note: 2008 = financial year 2008/09, etc.

Figure 8: *Temporal trend in proportion of infants who underwent a procedure and were diagnosed antenatally (financial years 2012/13 to 2017/18): any cardiac malformation (All), hypoplastic left heart syndrome (HLHS), and transposition of great arteries with intact ventricular septum (TGA-IVS).*



Note: The audit continues to use the metric of how many infants had had an antenatal diagnosis irrespective of how many procedures they may have had in the first year of life (excluding isolated procedures for a secundum atrial septal defect or persistent patent arterial duct, as these cannot be diagnosed before birth). This means that these figures cannot be directly compared to annual reports before 2015/16 from NICOR as previously the analyses looked at the number of procedures in infancy (sometimes 2 or 3) where an antenatal diagnosis had been made (over 50% in 2015/16).

Overall at regional level there are fewer areas whose centres are achieving an antenatal detection rate for all infants requiring a procedure in the first year of life of under 50% in 2017/18 than in the combined three years of 2015/16-2017/18 (Figure 9). Despite this encouraging trend, there remains considerable regional variation in diagnostic rates for congenital heart disease before birth as shown in Table 14 with some centres achieving over 70%, and others only 35%.

Using the National Fetal Cardiology Group target mean overall detection rate of 75%, this 2017/18 funnel plot shows graphically

the regions where additional training for obstetric sonographers may be best targeted in those centres scoring below this target and particularly if below the actual mean of 55.9%. Of note is that most regions have many centres sited within them, especially highly populated ones, such as Thames Valley and London, with likely important centre-level variation in diagnostic rates within a region. Individual centres, however, should have a good grasp of how successful they are and be alerted of missed cases, mostly via links through their local fetal and paediatric cardiologist.

Figures 9(a&b): *Funnel plots showing the overall antenatal detection rates by region, 2015/16-2017/18 (upper panel) and 2017/18 (lower panel), for infants who underwent a procedure. See Table 14 for key to numbered regions*

Figure 9a: *Overall antenatal detection rates by region, 2015/16-2017/18*

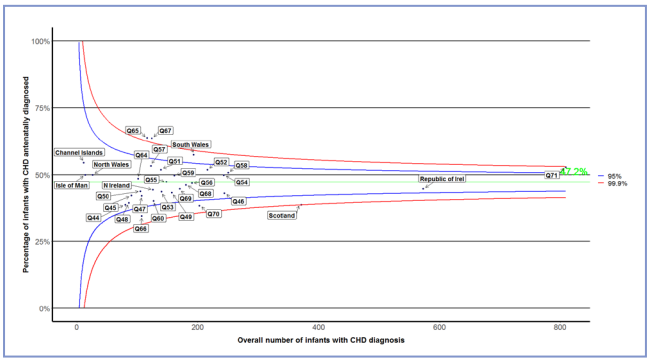


Figure 9b: *Overall antenatal detection rates by region, 2017/18*

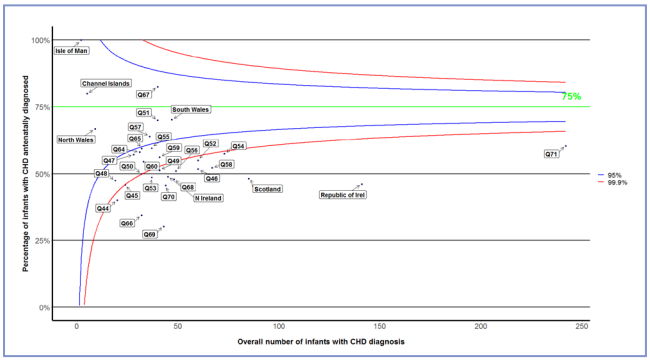


Table 14: *Regional and national variation in antenatal diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2017/18 in the UK and Republic of Ireland.*

Nation or English Local Area Team (LAT)/ South Wales Local Health Board	Overall diagnosis	Antenatally diagnosed (%)
Channel Islands	5	80.0%
England	1263	54.4%
Isle of Man	<3	100.0%
Northern Ireland	45	48.9%
Republic of Ireland	141	46.0%
Scotland	85	48.2%
Wales	56	69.6%
Local Area Team in England		
Q44. Cheshire, Warrington and Wirral	20	40.0%
Q45. Durham, Darlington and Tees	24	45.8%
Q46. Greater Manchester	60	51.7%
Q47. Lancashire	28	57.1%
Q48. Merseyside	19	47.4%
Q49. Cumbria, Northumberland, Tyne and Wear	41	51.2%
Q50. North Yorkshire and Humber	32	50.0%
Q51. South Yorkshire and Bassetlaw	40	70.0%
Q52. West Yorkshire	60	55.0%
Q53. Arden, Herefordshire and Worcestershire	37	48.6%
Q54. Birmingham and The Black Country	73	57.5%
Q55. Derbyshire and Nottinghamshire	37	59.5%
Q56. East Anglia	49	51.0%
Q57. Essex	36	63.9%
Q58. Hertfordshire and The South Midlands	67	52.2%
Q59. Leicestershire and Lincolnshire	41	56.1%
Q60. Shropshire and Staffordshire	33	54.5%
Q64. Bath, Gloucestershire, Swindon and Wiltshire	31	58.1%
Q65. Bristol, North Somerset, Somerset and South Gloucestershire	32	59.4%
Q66. Devon, Cornwall and Isles of Scilly	32	34.4%
Q67. Kent and Medway	40	82.5%
Q68. Surrey and Sussex	48	47.9%
Q69. Thames Valley	43	30.2%
Q70. Wessex	44	45.5%
Q71. London	242	60.3%
North Wales	9	66.7%
South Wales	47	70.2%
- Local Health Board 7A2	7	71.4%
- Local Health Board 7A3	8	75.0%
- Local Health Board 7A4	10	80.0%
- Local Health Board 7A5	10	60.0%
- Local Health Board 7A6	10	60.0%
- Local Health Board 7A7	<3	100.0%
Overseas	46	39.1%
Unknown	1	100.0%
Total	**1590**	**53.5%**

N.B. Data are suppressed where case numbers are less than three. Percentages have been adjusted accordingly. This process was conducted for data protection reasons, to ensure anonymity of the patient data included in reporting.

Antenatal detection rates are much higher for babies with more severe, functionally single ventricle lesions (such as hypoplastic left heart syndrome), as such defects are more easily seen by the obstetric sonographer given an abnormal four chamber view.[15]

However, many important congenital heart malformations, especially where the great arteries are not normal, are technically more difficult to detect.

Mandatory antenatal detailed screening for abnormalities of the great arteries has only relatively recently been introduced by the NHS Fetal Anomaly Screening Programme.[16]

The Congenital Audit has again examined the success of antenatal screening to detect two contrasting specific heart malformations and whether the baby had undergone a procedure in the first 6 months after birth (as would be expected with these diagnoses):

- hypoplastic left heart syndrome (HLHS) – as an example of a malformation with a functionally single ventricle circulation
- transposition of great arteries with intact ventricular septum (TGA-IVS) – as an example of when there is a major great arterial malformation.

In both conditions, infants often need an emergency procedure within hours of delivery followed by major surgery within a few days of birth. Research has shown that an antenatal diagnosis improves survival with fewer complications and better neurocognitive outcomes.[17,18] An antenatal diagnosis will impact on the place and timing of delivery with care often transferred to the tertiary congenital heart centre or the nearest obstetric unit, so that the paediatric cardiologist can be rapidly at the bedside if required.

Figure 10 and Table 15 show an expected continued high diagnosis rate for hypoplastic left heart syndrome, rising from about 65% 10 years ago to now over 90% in 2017/18. There also continues to be an impressive increase in the rate of antenatal diagnostic success for transposition of the great arteries and intact ventricular septum, rising from just 26% in 2007/08 to over 75% in 2017/18, now exceeding recent international figures.[19]

All of these antenatal diagnosis rates are probably an underestimate of national and local antenatal detection rates as they do not take into account four outcomes following a fetal cardiac diagnosis: fetal death (spontaneous or termination of pregnancy), perinatal death before a procedure was possible, less severe malformations not requiring a procedure in infancy, and where a decision was made not to intervene due to the complexity of the heart abnormality or associated comorbidities (compassionate care).

Table 15: *10-year detection rates for HLHS and TGA-IVS, antenatally diagnosed and who underwent a procedure within 6 months of birth.*

Year	Overall HLHS diagnosis		TGA-IVS diagnosis	
	Number	% Antenatally diagnosed	Number	% Antenatally diagnosed
2008	91	64.8	83	19.3
2009	109	68.8	89	23.6
2010	94	72.3	101	28.7
2011	113	76.1	83	37.3
2012	99	84.8	86	38.4
2013	107	83.2	84	38.1
2014	106	84.0	77	54.5
2015	100	87.0	87	55.2
2016	98	82.7	70	65.7
2017	86	93.0	66	75.8
Total	**1115**	**78.6%**	**826**	**42.1%**

Note: HLHS = hypoplastic left heart syndrome; TGA-IVS = transposition of the great arteries with an intact ventricular septum

This is likely to have had an important influence on the outcomes after the arterial switch procedure, not only with respect to mortality, but also to pre- and post-procedural morbidity and support for families. However, although there has been significant improvement in all regions over the years, with less variance than last year's report, there remain considerable differences overall (Table 14) and for transposition of the great arteries, with only 50% detection rate in some regions compared with up to 100% in others (Table 16).

The funnel plots in Figure 10 demonstrate that the regional variability for HLHS is comparatively low with only 3 regions underperforming (under 80%) for this relatively easily diagnosed condition, as an example of what can be achieved for those with a functionally single ventricle circulation. The lower panel continues to show significant variation for TGA-IVS with many under 60%, suggesting that this and other great arterial malformations, such as tetralogy of Fallot, remain challenging diagnoses for many centres.

Many of the best regions in this three-year period have comparatively low volumes of both diagnoses. Again, it is worth emphasising that these rates do not account for inter-centre variation in the majority of regions, given the presence of several centres within their boundaries. As said, individual centres should have an understanding of how successful they are and of any missed cases, following feedback from their local fetal and-or paediatric cardiologist.

Figures 10 (a&b): *Funnel plots showing the antenatal detection rates by region 2015/16-2017/18 for hypoplastic left heart syndrome (upper panel) and transposition of great arteries with intact ventricular septum (lower panel), for infants who underwent a procedure at under 6 months of age. See Table 16 for key to numbered regions.*

Figure 10a: *Hypoplastic left heart syndrome*

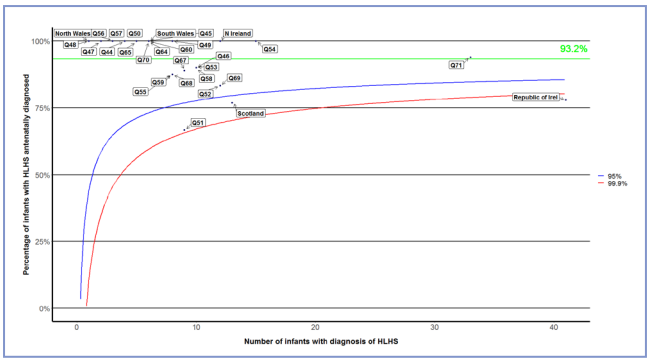


Figure 10b: *Transposition of great arteries with intact ventricular septum*

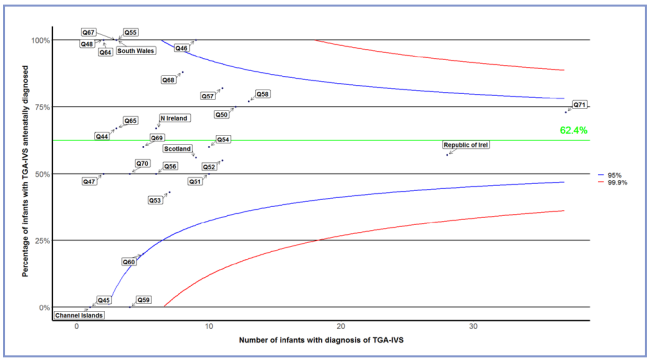


Table 16: *Regional and national variation in antenatal diagnosis rates of infants with HLHS and TGA-IVS who underwent a procedure within 6 months of birth: 2015/16 to 2017/18.*

Nation or English Local Area Team	HLHS diagnosis	% Antenatally diagnosed	TGA -IVS diagnosis	% Antenatally diagnosed
Channel Islands	0	-	<3	0%
England	211	88.6%	177	65.5%
Isle of Man	0	-	0	-
Northern Ireland	12	100%	6	67%
Republic of Ireland	41	78.0%	28	57%
Scotland	13	76.9%	9	56%
North Wales	1	100.0%	0	-
South Wales	6	100.0%	3	100%
Local Area Team in England				
Q44. Cheshire, Warrington and Wirral	4	100.0%	3	67%
Q45. Durham, Darlington and Tees	6	100.0%	1	0%
Q46. Greater Manchester	10	90.0%	9	100%
Q47. Lancashire	2	100.0%	2	50%
Q48. Merseyside	2	100.0%	2	100%
Q49. Cumbria, Northumberland, Tyne and Wear	8	100.0%	0	-
Q50. North Yorkshire and Humber	5	100.0%	12	75%
Q51. South Yorkshire and Bassetlaw	9	66.7%	10	50%
Q52. West Yorkshire	12	83.3%	11	55%
Q53. Arden, Herefordshire and Worcestershire	10	90.0%	7	43%
Q54. Birmingham and The Black Country	15	100.0%	10	60%
Q55. Derbyshire and Nottinghamshire	8	87.5%	3	100%
Q56. East Anglia	3	100.0%	6	50%
Q57. Essex	4	100.0%	11	82%
Q58. Hertfordshire and The South Midlands	10	90.0%	13	77%
Q59. Leicestershire and Lincolnshire	8	87.5%	4	0%
Q60. Shropshire and Staffordshire	6	100.0%	5	20%
Q64. Bath, Gloucestershire, Swindon and Wiltshire	6	100.0%	2	100%
Q65. Bristol, North Somerset, Somerset and South Gloucestershire	5	100.0%	3	67%
Q66. Devon, Cornwall and Isles of Scilly	0	-	0	-
Q67. Kent and Medway	9	88.9%	3	100%
Q68. Surrey and Sussex	8	87.5%	8	88%
Q69. Thames Valley	12	83.3%	5	60%
Q70. Wessex	6	100.0%	4	50%
Q71. London	33	93.9%	37	73%
Overseas	1	0.0%	1	0%
Unknown	10	30.0%	4	25%
Total	**284**	**87.3%**	**223**	**64.6%**

N.B. Data are suppressed where case numbers are less than three. Percentages have been adjusted accordingly. This process was conducted for data protection reasons, to ensure anonymity of the patient data included in reporting.

Note: HLHS = hypoplastic left heart syndrome; TGA-IVS = transposition of great arteries with intact ventricular septum.

The continued major rise in detection rates in the last few years for transposition of the great arteries, is attributable to the introduction of the mandatory 3-vessel and tracheal view in 2016 to the fetal cardiac sonographer protocol with the preceding 2-year national training programme.[16] However, it is also a tribute to individual local maternity centres introducing intensive training for their obstetric sonographers, often aided by the Tiny Tickers charity, as illustrated in the report provided by Russells Hall Hospital in Dudley, West Midlands in the main NCAP report.

It is important to ensure that feedback mechanisms and links are in place between the Congenital Audit, the fetal cardiology community and antenatal ultrasound scanning departments to enable learning related to congenital heart cases which have not been detected. The audit will facilitate this by passing on these results to the UK National Fetal Cardiology Group and Tiny Tickers Charity, enabling its members to target individual centres most in need of improvement for staff training and optimisation of ultrasonography equipment. Results will also be shared with the relevant Clinical Commissioning Groups (CCGs).

4. DRIVING FUTURE QUALITY IMPROVEMENT THROUGH AUDIT

Next year, it is anticipated that the design and conduct of the NCAP audits will continue to evolve to inform and drive future quality improvement. Major initiatives include:

1. **Data quality.** The Congenital Audit reviews the care for a smaller number of patients than the other cardiac audits and this provides its own challenges in statistical analysis. This is one of the reasons why data are analysed over a three-year rolling programme, allowing the collection of data on sufficiently large groups of patients undergoing a variety of specific procedures to allow for reliable comparisons. Given the large number of different cardiac malformations with associated specific surgical and/or transcatheter procedures, relatively small variations in data quality can result in different conclusions about the quality of care. The Congenital Audit therefore uses a rigorous quality assurance validation process to ensure that submitted data quality is of a high standard, being both accurate and pertinent, as well as ensuring all eligible patients are captured (case ascertainment). This audit has therefore developed a unique Data Quality Indicator (DQI) score, which provides confidence in the data submitted and their analyses (see appendix 2 for details). Along with the UK's ability to independently verify life status through use of the patients' NHS numbers and reporting of deaths to NHS Digital, the Congenital Audit's validation protocols have internationally been recognised as exemplary.[20]

   However, this year's analyses of new data fields relating particularly to 'unplanned re-operations' and post-procedural complications found major issues with data quality, with incomplete data submissions as well as incongruities between data fields. The same was found related to the specific adult congenital heart disease comorbidity fields. The Congenital Audit therefore plans to:

   a. Send summary reports to all centres with respect to data quality issues in the 2015/18 database to ask that missing data be added, and errors / inconsistencies be corrected or resolved during the first 9 months of the 2019/20 audit cycle.

   b. Instigate a process for more frequent checking of data quality during the 2019/20 data cycle, identifying specific concerns to each centre where data are either missing or considered to be inconsistent or invalid. The expectation will be that the centre will correct any errors and supply missing data before resubmitting within the following 2-3 months.

   Once data quality has been secured with retrospective data corrections and entries, the planned analyses focussing on 'unplanned re-operations' and other post-procedural complications can go ahead using 4 years of data (2015/16-2018/19). It will also be an opportunity to revisit and refine the STAT adult congenital heart procedure methodology as it relates to NCHDA data.

2. **PRAiS2 risk model.** The audit co-developed a unique risk model (PRAiS2) that allows hospitals to see how they are doing with respect to their own patient case mix, comparing monthly outcomes to what is predicted nationally and in their own practice. NHS England has commissioned an independent provider to augment the PRAiS2 software to include three control limits so that centres and commissioners (if required) will have early warning of any 'breaches' of these limits so that the issues can be rapidly resolved in house as necessary. The audit will participate in ensuring the data upon which such findings are made remain of the highest accuracy and quality.

3. **The NCHDA web portal.** The presentation of portal data will be reviewed and reconfigured to allow easy-to-access centre level data that are both comprehensive and understandable to parents and families, specialist congenital heart clinicians and commissioners.

4. **Fetal database.** NCHDA has developed a unique 42 field fetal database that will link seamlessly to the current postnatal procedure-based platform. This aims to improve the information on antenatal diagnosis and outcome, linking to postnatal outcomes, so as to report national outcomes by congenital heart disease diagnosis rather than procedure for the first time. The database is complete and operational but needs to be upgraded to the new NICOR database platform (QReg5) that NCHDA will shortly move to.

   This expansion is supported by Public Health England, HQIP and NHS England. Part of this project is for there to be a bidirectional link to the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) for data validation and case ascertainment purposes. The previous data-sharing agreement needs to be revised given NICOR's move to Barts Health NHS Trust in 2017 to enable bidirectional data-sharing between NCHDA and NCARDRS to optimise data quality and full case ascertainment.

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6. APPENDIX 1: COMPLICATION DEFINITIONS

Timescale for identification	Definition
Acute neurological event	
Includes neurological morbidities that, based on best clinical judgement, arose as new findings around the time of surgery that were detected within 30 days of the procedure. It is recognised that in certain circumstances such as where a child is very sick on life support, pre-procedure assessment is challenging, in these circumstances as full an evaluation as possible to be completed, incorporating serial assessments over time.	Neurological events including: seizure, abnormal movement (includes choreiform or athetoid), focal neurological deficit (includes hemiplegia and monoplegia), intracranial haemorrhage, stroke, brain death, reversible ischaemic neurological dysfunction, hypoxic ischaemic encephalopathy, spinal cord ischaemia, basal ganglia damage, or brain stem injury (includes abnormal cough or gag reflex). Includes a new abnormality in any of the following: Electroencephalogram, Brain scan (either CT or MRI), Clinical evaluation (seizures or movement disorder, focal neurological signs, generalised neurological signs, altered conscious level including brain death)
Need for renal replacement therapy	
Includes renal replacement therapy when initiated as a new support at any time from the start of the postoperative admission to the intensive care unit (ICU) up until 30 days following the procedure.	The child requires renal replacement therapy (peritoneal dialysis or haemofiltration) for renal failure (oligo-anuria of <0.5 ml/kg/hour and elevated creatinine level for age), and-or fluid overload. In patients where renal support is required alongside extracorporeal life support, the primary morbidity is viewed as extracorporeal life support. The measurement protocol is simply the presence of (new) renal support and excludes renal support on extracorporeal life support.
Extracorporeal life support	
Extracorporeal life support within 30 days following a procedure, including the rare cases when a child was on extracorporeal life support before surgery.	This morbidity is defined by the presence of an extracorporeal life support system connected to the patient following the operation, whether it was placed in the operating theatre or in the ICU, and whether the indication was cardiac arrest, low cardiac output state, poor cardiac function, arrhythmia, residual or recurrent cardiac lesion, pulmonary including pulmonary hypertension, or sepsis. It is recognised that children on extracorporeal life support following paediatric cardiac surgery have high rates of other complications including renal support, bleeding, sepsis, sternal reopening, and cardiac arrest. Where such complications arise as part of extracorporeal life support, the morbidity is defined as extracorporeal life support.
Prolonged pleural effusion or chylothorax	
Prolonged pleural effusion is a post-procedural effusion with duration greater than 10 days. Chylothorax is diagnosed from after surgery and within 30 days after the procedure.	Either a chylous pleural effusion or significant chylous pericardial effusion or significant chylous ascites or a prolonged non-chylous effusion that necessitates thoracic drainage at least 10 days following index cardiac surgery. Chylous effusions are characterised by milky appearance and a pleural fluid white blood cell count of >1000 cells/µl with lymphocytes >80%. If the child is on normal feeds the triglyceride level in the pleural fluid will be >1.1 mmol/L or the ratio between the pleural triglyceride level and the serum triglyceride level will exceed 1.

7. APPENDIX 2: DATA QUALITY

DATA VALIDATION AND DATA QUALITY INDICATOR SCORES

A2.1 WHAT IS THE NCHDA VALIDATION PROCESS AND THE DATA QUALITY INDICATOR (DQI) SCORE?

The Congenital Audit uses a multifaceted and robust quality assurance validation process to ensure that submitted data are high quality, accurate and comprehensive, whilst ensuring full case ascertainment with all relevant patients included in centre submissions. All paediatric centres and larger adult contributing centres have site visits by a volunteer clinician with either full audio-visual teleconference, or on-site support, from the NCHDA Clinical Auditor. Until 2014, all centres who submitted ten or more cases (therapeutic surgery and/or interventional catheter procedures) to the NCHDA qualified for a validation visit. Since 2015 only Level 1 centres have the site validation visits with a clinician and/or the NCHDA Clinical Auditor. Prior to 2017 the Clinical Auditor attended all site visits. These NCHDA data are also approved and signed off at the end of each financial year and data collection cycle by the contributing hospital as being accurate and the same as the data submitted to the NCHDA database; a process known as reverse validation.

There are three stages to the validation process. The first involves a review of 20 randomly selected hospital records of submitted Congenital Audit patients. The previously submitted data for these 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 is expected to be greater than 90% (see Section A2.6 below) for further details and how this is calculated). A DQI score of over 95% is deemed excellent.

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.

All Level 1 hospitals that undertake procedures on patients with congenital heart disease and submit data to NCHDA are invited to participate in either an on-site or a supported remote validation visit. Private hospitals and hospitals and institutions that submit data to NCHDA are also given the opportunity to participate if they wish to.

The Case Note Audit at a site validation visit provides a snapshot of the data quality systems and processes at a centre submitting data to the NCHDA. The DQI score acts as a quality indicator benchmark for data completeness and accuracy, giving an insight on the level of value, importance and esteem with which the NCHDA data are regarded at each visited centre. The DQI calculation is provided within 48 hours of a site visit offering almost immediate feedback to clinicians and data managers. This benchmark is now included as an annual metric in the NHS England Specialist Services Quality Dashboard for congenital cardiac services that each centre submits data to, on an annual and quarterly basis.

Face to face, on-site in person support at a validation visit by both an external clinician and the NCHDA Clinical Auditor facilitates two-way teaching and learning activity as well as peer review and support. Trainee clinicians and database managers from other NCHDA centres are encouraged to visit other centres undergoing a validation visit to observe different work practices and procedures and strengthen network support, providing an excellent learning and development opportunity.

A2.2. REMOTE VALIDATION

All stakeholders including those who receive a site validation visit are now sent a prepared print out of their activity broken down into specific procedure groups and life status at 30 days post procedure and asked to check and verify it with confirmation that it is correct. This is a remote validation and no DQI is calculated.

A2.3. DATA QUALITY INDICATOR (DQI) SCORES

The NCHDA standard for data quality is 90% accuracy across all domains. All 16 centres that had a site visit had DQI scores of 90% and above for data submitted in 2017/18. Above 95% is excellent and it is noteworthy that many hospitals are currently over 98%. Just one hospital scored below 95% at 94.5% for 2017/18, which can be partly attributed to a slightly lower investment in specific supporting staff. Overall the average DQI has improved year on year for paediatric centres, although more erratic for adult congenital heart disease (ACHD) centres as shown in Table 17.

Just three ACHD centres had DQI validation visits during 2018 due to decommissioning of Manchester Royal Infirmary as a Level 1 provider. The Golden Jubilee Hospital in Glasgow, another Level 1 provider, decided that they were unable to participate. In December 2018 Liverpool Heart and Chest Hospital commenced as a full Level 1 service and will receive a DQI validation visit in 2019.

Table 17: *DQI overall scores over 5 years by centre*

Paediatric/Mixed Practice Hospitals	Centre Code	2013/14	2014/15	2015/16	2016/17	2017/18
Belfast, Royal Victoria Hospital	RVB	95.75	98.75	98.25	94.50	*
Birmingham Children's Hospital	BCH	96.50	98.50	97.75	99.50	99.00
Bristol Royal Hospital for Children	BRC	96.50	94.50	98.60	98.75	99.00
Dublin, Our Lady's Children's Hospital	OLS	96.50	97.25	94.50	97.00	98.25
Glasgow, Royal Hospital for Sick Children	RHS	98.50	98.50	99.25	99.25	99.50
Leeds General Infirmary	LGI	97.75	97.00	97.75	98.00	99.00
Leicester, Glenfield Hospital	GRL	90.50	94.00	97.00	97.25	97.00
Liverpool, Alder Hey Children's Hospital	ACH	94.75	97.25	95.25	97.50	98.00
London, Evelina London Children's Hospital	GUY	97.00	97.50	99.25	96.00	99.00
London, Great Ormond Street Hospital for Children	GOS	99.50	99.50	97.00	99.50	95.00
London, Harley Street Clinic	HSC	95.75	94.50	95.50	95.75	95.50
London, Royal Brompton Hospital	NHB	98.00	99.00	99.25	99.25	99.00
Newcastle, Freeman Hospital	FRE	96.75	97.25	97.50	99.00	98.75
Southampton, Wessex Cardiothoracic Centre	SGH	98.00	97.50	95.75	99.00	98.75
Adult only Hospitals						
Belfast, Royal Victoria Hospital	RVB	na	na	na	na	95.00
Birmingham, Queen Elizabeth Hospital	QEB	77.00	79.00	75.25	92.50	94.50
Glasgow, Golden Jubilee Hospital	GJH	97.50	94.50	92.50	99.00	**
London, University College/St Bartholomew's Hospital	UCL/SBH	89.50	94.25	93.25	96.75	96.50
Manchester Royal Infirmary	MRI	95.00	97.00	97.70	98.50	***

Table key			
*	ACHD only		<90
**	No data submitted		90 to <95
***	Service transferred		95 to <98
			>=98

It is suggested that the key requirements for a good or excellent DQI are:

- Embedded culture of gold standard quality assurance of data collection processes, internal reviews and timely external submission to meet national deadlines
- Well trained and well supported Database Managers (DBM)
- DBM must have protected time for role and NCHDA suggest 1.0wte per 400 procedures in NCHDA and 1.0WTE assistant DBM (NHSE Congenital Cardiac Standards May 2016)[21]
- A specific, dedicated database
- Access to dedicated database at all points and areas of service.
- Clinical Lead to actively lead local data validation
- Train all staff in the importance of timely data collection and internal validation
- All clinicians 'buy in' and own the data
- Encourage trainees to participate in data collection and validation
- Trainees encouraged to participate in external validation visits
- Regular (monthly depending on volumes) reverse validation of data

A2.4. FUTURE PLANS TO IMPROVE SUBMITTED DATA QUALITY

The DQI does not necessarily reflect the data quality in the whole dataset as it is based only on an in-depth assessment of 20 randomly selected case notes. As detailed on page 43, concerns remain about the data completeness and quality for specific data fields used particularly for new metrics such as procedural complications and unplanned re-interventions. The Congenital Audit plans to address the deficiencies prospectively by instigating a process for more frequent data quality assessments for all reporting centres, as well as retrospectively 'filling in the gaps' and dealing with inconsistencies for data submitted since 2015.

A2.5. DATA QUALITY INDICATOR SCORES – OVERALL, CATHETER AND SURGERY

Table 18 shows the DQI for Mixed Practice and Paediatric hospitals, with the overall DQIs and the individual DQIs for catheter interventions and surgical operations across 3 data collection years, 2013/14 -2017/18. Comparison between the individual DQI scores of centres is not always appropriate due to the varying complexity of case mix, and the numbers and types of procedures performed within the 20 randomly selected cases chosen.

Table 18: *DQI scores for mixed practice and paediatric congenital heart hospitals 2015/16, 2016/17 and 2017/18.*

Paediatric and Mixed Practice Hospitals														
DQI% for 2015/16 data based on the 20 case note review May-Nov 2016					DQI% for 2016/17 data based on the 20 case note review May-Nov 2017					DQI% for 2017/18 data based on the 20 case note review May-Oct 2018				
Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen
Belfast Royal Victoria	RVB	98.25	98.25	98.5	Belfast Royal Victoria	RVB	94.5	96.25	94	Belfast Royal Victoria	RVB	Now commissioned as ACHD only		
Birmingham Childrens Hospital	BCH	97.75	98.75	96.75	Birmingham Childrens Hospital	BCH	99.5	100	99.5	Birmingham Childrens Hospital	BCH	99	98.75	99
Bristol Royal Childrens Hospital	BRC	98.60	99.25	98.25	Bristol Royal Childrens Hospital	BRC	98.75	99.25	98	Bristol Royal Childrens Hospital	BRC	99.00	99.25	99
Dublin, Our Lady's Hospital	OLS	94.5	94.25	95	Dublin, Our Lady's Hospital	OLS	97	96.75	97.5	Dublin, Our Lady's Hospital	OLS	98.25	99	98
Glasgow Royal Hospital for Sick Children	RHS	99.25	98.75	99.25	Glasgow Royal Hospital for Sick Children	RHS	99.25	99.25	99.75	Glasgow Royal Hospital for Sick Children	RHS	99.5	99.5	100
Leeds General Infirmary	LGI	97.75	98.5	97.25	Leeds General Infirmary	LGI	98	99	97.5	Leeds General Infirmary	LGI	99	98.25	99.5
Leicester Glenfield Hospital	GRL	97	97	97.25	Leicester Glenfield Hospital	GRL	97.25	94	98	Leicester Glenfield Hospital	GRL	97	97	94.5
Liverpool Alder Hey Childrens Hospital	ACH	95.25	94	96.25	Liverpool Alder Hey Childrens Hospital	ACH	97.5	97	99	Liverpool Alder Hey Childrens Hospital	ACH	98	96.25	95
London Evelina Childrens Hospital	GUY	99.25	99.25	99.5	London Evelina Childrens Hospital	GUY	96	94.75	97	London Evelina Childrens Hospital	GUY	99	99.50	98.75
London Great Ormond Street	GOS	97	97.25	96.65	London Great Ormond Street	GOS	99.5	99.75	98.75	London Great Ormond Street	GOS	95	95.5	95
London Harley Street Clinic	HSC	95.5	95.5	93.5	London Harley Street Clinic	HSC	95.75	97.75	93.25	London Harley Street Clinic	HSC	95.5	96.25	95
London Royal Brompton & Harefield	NHB	99.25	99.5	98.75	London Royal Brompton & Harefield	NHB	99.25	99.25	98.75	London Royal Brompton & Harefield	NHB	99	98	99.25
Newcastle Freeman	FRE	97.5	98.5	97	Newcastle Freeman	FRE	99	98.25	99	Newcastle Freeman	FRE	98.75	98.25	99.75
Southampton on Wessex Cardiothoracic Centre	SGH	95.75	98	93	Southampton on Wessex Cardiothoracic Centre	SGH	99	99.25	99	Southampton on Wessex Cardiothoracic Centre	SGH	98.75	98.25	99

Table 19: *DQI scores for adult only congenital heart centres which received onsite validation visits.*

ACHD Hospitals who received on site validation visits														
DQI% for 2015/16 data based on the 20 case note review May 2016 - Jan 2017					DQI% for 2016/17 data based on the 20 case note review May - Nov 2017					DQI% for 2017/18 data based on the 20 case note review May - Oct 2018				
Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen
										Belfast Royal Victoria	RVB	95	93.5	96
Birmingham Queen Elizabeth Hospital	QEB	75.25	66.75	89.75	Birmingham Queen Elizabeth Hospital	QEB	92.5	89.75	95.5	Birmingham Queen Elizabeth Hospital	QEB	94.5	94.5	79.5
Glasgow Golden Jubilee	GJH	92.5	93.25	92	Glasgow Golden Jubilee	GJH	99	99	99	Glasgow Golden Jubilee	GJH	No Data Submitted		
Liverpool Heart & Chest Hospital	BHL	Remote Validation			Liverpool Heart & Chest Hospital	BHL	Remote Validation			Liverpool Heart & Chest Hospital	BHL	Remote validation, commissioned Level 1 from June 2018		
London University College/St Bartolomew's	UCL/ SBH	93.25	91.75	93.75	London University College/St Bartolomew's	UCL/ SBH	96.75	97.75	96	London University College/St Bartolomew's	UCL/ SBH	96.5	100	96.5
Manchester Royal Infirmary	MRI	97.7	97	96.75	Manchester Royal Infirmary	MRI	98.5	98	98	Manchester Royal Infirmary	MRI	Decomissioned from Level 1 July 2017		

For the year 2017/18 the following centres changed designation or did not participate:

- Belfast Royal Victoria Hospital became an adult congenital heart disease (ACHD) service only
- Glasgow Golden Jubilee Hospital - Level 1 ACHD centre chose to not participate
- Manchester Royal Infirmary ceased to be a Level 1 provider of ACHD services

Table 20: *Remotely validated adult only congenital heart centres.*

These centres who submit to NCHDA are small volume Level 2 centres undertaking very small numbers of predominantly catheter interventions such as atrial septal defect or patent foramen ovale (PFO) closure. For full details of procedural activity up to and including 2015/16, see the NCHDA web portal:

https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/WSummaryYears?openview&RestrictToCategory=2015&start=1&count=500 and for 2014/15-2017/18 onwards please see here:

https://web.nicor.org.uk/CHD/an_paeds.nsf/vwContent/NCHDA%20Report%20Analyses%202014-17?Opendocument

April - March 2015/16					April - March 2016/17					April - March 2017/18				
Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen
Basildon Essex Cardiothoracic Centre	BAS	Remote validation			Basildon Essex Cardiothoracic Centre	BAS	Remote validation			Basildon Essex Cardiothoracic Centre	BAS	Remote validation		
Blackpool Victoria Hospital	VIC	Remote validation			Blackpool Victoria Hospital	VIC	Remote validation			Blackpool Victoria Hospital	VIC	Remote validation		
Brighton Royal Sussex County Hospital	RSC	Remote validation			Brighton Royal Sussex County Hospital	RSC	Remote validation			Brighton Royal Sussex County Hospital	RSC	Remote validation		
Cardiff University Hospital of Wales	UHW	Remote validation			Cardiff University Hospital of Wales	UHW	Remote validation			Cardiff University Hospital of Wales	UHW	Remote validation		
Liverpool Heart & Chest Hospital	BHL	Remote validation			Liverpool Heart & Chest Hospital	BHL	Remote validation			Liverpool Heart & Chest Hospital	BHL	Remote validation		
London Hammersmith Hospital	HAM	Remote validation			London Hammersmith Hospital	HAM	Remote validation			London Hammersmith Hospital	HAM	Remote validation		
London Kings College Hospital	KCH	Remote validation			London Kings College Hospital	KCH	Remote validation			London Kings College Hospital	KCH	Remote validation		
London St Georges Hospital	GEO	Remote validation			London St Georges Hospital	GEO	Remote validation			London St Georges Hospital	GEO	Remote validation		
Manchester Royal Infirmary	MRI	Previously Level 1 Centre			Manchester Royal Infirmary	MRI	Previously Level 1 Centre			Manchester Royal Infirmary	MRI	Remote validation		
Nottingham City Hospital	CHN	Remote validation			Nottingham City Hospital	CHN	Remote validation			Nottingham City Hospital	CHN	Remote validation		
Sheffield Northern General Hospital	NGS	Remote validation			Sheffield Northern General Hospital	NGS	Remote validation			Sheffield Northern General Hospital	NGS	Remote validation		
Oxford John Radcliffe	RAD	Remote validation			Oxford John Radcliffe	RAD	Remote validation			Oxford John Radcliffe	RAD	Remote validation		
Stoke University Hospital of North Staffordshire	STO	Remote validation			Stoke University Hospital of North Staffordshire	STO	Remote validation			Stoke University Hospital of North Staffordshire	STO	Remote validation		
Wolverhampton heart & Chest hospital	NCR	Remote validation			Wolverhampton heart & Chest hospital	NCR	Remote validation			Wolverhampton heart & Chest hospital	NCR	Remote validation		

Table 21: *Non-participating adult only congenital heart centres.*

April - March 2015/16					April - March 2016/17					April - March 2017/18				
Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen	Hospital	Centre Code	Overall DQI%	DQI for Surgery case notes seen	DQI for Catherter Procedure case notes seen
Bristol Spire	GHB	Did Not Participate			Bristol Spire	GHB	No Data Submitted			Bristol Spire	GHB	No Data Submitted		
Cambridge Papworth*	PAP	83.5	84	82.4	Cambridge Papworth	PAP	No Data Submitted			Cambridge Papworth	PAP	No Data Submitted		
										Glasgow Golden Jubilee	GJH	No Data Submitted		

** Cambridge Papworth participated for this year only.*

A2.6 DQI PROCESS AND CALCULATIONS

The NCHDA uses a rigorous validation process comprising site visits by a volunteer clinician to all contributing centres with support from the NCHDA Clinical Auditor. The purpose is to ensure full case ascertainment and to validate the accuracy of the data submitted to the audit. Twenty patients sample case notes are randomly selected from the submitted data from the year under review for closer scrutiny of data accuracy and completeness. The selection of notes takes place approximately 4 weeks prior to the site visit. The same data fields are checked in the hospital case notes against the data that has been submitted. Where there is a discrepancy a query is raised.

The case note data are split into 4 domains or sections that cover 57 data fields, demographics (name, date of birth, NHS number etc.), pre-procedure (height and weight, diagnoses, previous procedures etc.), procedure (the names of the operations or interventions performed, the names of the operators, type of procedure, bypass or catheter time, etc.) and outcome (length of ventilation, complications, date of discharge or death, discharge destination).

The DQI is produced by taking the mean of the four NCHDA domains: Demographics; Pre-procedure; Procedure & Outcome. Each domain is measured in a range from 1.00 to zero where 1.00 indicates that ALL records within the organisation have valid codes in ALL the fields used to form that particular domain.

If any of the fields within the record contain invalid or missing values, a counter is incremented by 1. The domain is then scored by calculating the proportion of records where all the fields have valid values i.e.

$$\frac{1 - \text{number of records with any invalid value}}{\text{total number of records examined}}$$

For example, if a centre had 40 records and 10 of them were found to contain an invalid or discrepant value in one or more of the above fields, then the component score is 1- (10/40) = 0.75. The DQI is simply the average of all the domains, expressed as a percentage.

For example, if the same centre had scores of:

Demographics 0.75, Pre-procedure 0.95, Procedure 1.00, Outcome 1.00, then the DQI is:

$$\frac{(0.75 + 0.95 + 1 + 1)}{4} \times 100 = 92.5\%$$

The principle advantages of this DQI system are that it identifies the nature of any prevailing data issues. In this example there appears to be a problem with the quality and accuracy of the demographics data. The cause for this may not be immediately clear but needs local investigation as to why this has happened and maybe a small change in the data gathering process at this point. Differential DQI is also calculated for catheter interventions and surgery as the number of variables may differ from centre to centre depending on the case mix of the randomly chosen notes and direct comparison between centres is therefore inappropriate except using the overall DQI.

Once any discrepancies that were identified during the site visit have been checked and any changes made to the submitted data, they are then signed off by each visited centre as being accurate by reverse checking with the NCHDA database submissions.

The Case Note Audit at a site validation visit provides a snapshot of the data quality systems and processes at a centre submitting data to the NCHDA. The DQI score acts as a quality indicator benchmark for data completeness and accuracy, giving an insight on the level of value, importance and esteem with which the NCHDA data are regarded at each visited Centre. The DQI calculation is provided within 48 hours of a site visit offering almost immediate feedback to clinicians and data managers. This benchmark is now included in the quarterly NHS England Commissioning for Quality and Innovation (CQUIN) dashboard data template that each centre has to complete (Link below).

https://www.england.nhs.uk/publication/specialised-services-quality-dashboards-women-and-children-metric-definitions-for-2018-19/

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This report is available online at https://www.nicor.org.uk/national-cardiac-audit-programme/congenital-heart-disease-in-children-and-adults-congenital-audit/

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NATIONAL INSTITUTE OF CARDIOVASCULAR OUTCOMES RESEARCH (NICOR)

NICOR is a partnership of clinicians, IT experts, statisticians, academics and managers who, together, are responsible for six cardiovascular clinical audits (the National Cardiac Audit Programme – NCAP) and a number of new health technology registries, including the UK TAVI registry. Hosted by Barts Health NHS Trust, NICOR collects, analyses and interprets vital cardiovascular data into relevant and meaningful information to promote sustainable improvements in patient well-being, safety and outcomes. It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) with funding from NHS England and GIG Cymru /NHS Wales, and additional support from NHS Scotland. Funding is being sought to aid the participation of hospitals in Northern Ireland, the Republic of Ireland and the private sector.

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SOCIETY FOR CARDIOTHORACIC SURGERY IN GREAT BRITAIN AND IRELAND (SCTS)

SCTS is an affiliated group of the Royal College of Surgeons of England and has charitable status. The Charity's objects are to enable surgeons to achieve and maintain the highest standards of surgical practice and patient care.

BRITISH CONGENITAL CARDIAC ASSOCIATION (BCCA)

The British Congenital Cardiac Association is a membership association that aims to support and represent all health professionals whose interest is in the practice or research of congenital heart disease in the adult or heart diseases in the fetus or child. The BCCA was approved as a charity in February 2017 with Charitable Incorporated Organisation status. The objectives of the BCCA are the advancement of health and education in all aspects of congenital cardiac diseases, in particular by: 1. Promoting the study and care of the fetus and child with heart diseases and the adult with congenital heart disease in the United Kingdom and Republic of Ireland; 2. Promoting and distributing study data pertaining to these problems and their prevention; 3. Promoting research in paediatric and congenital cardiology and to publish the useful results of such research; and 4. The improvement of knowledge of professionals, the public and the patients and their families of paediatric and congenital cardiology, through scientific and educational meetings.

BARTS HEALTH NHS TRUST

With a turnover of £1.5 billion and a workforce of around 17,000, Barts Health is a leading healthcare provider in Britain and one of the largest NHS Trusts in the country. The Trust's five hospitals – St Bartholomew's Hospital in the City, including the Barts Heart Centre, The Royal London Hospital in Whitechapel, Newham University Hospital in Plaistow, Whipps Cross University Hospital in Leytonstone and Mile End Hospital – deliver high quality compassionate care to the 2.5 million people of east London and beyond.

THE HEALTHCARE QUALITY IMPROVEMENT PARTNERSHIP (HQIP)

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 in patient outcomes, and in particular, to increase the impact that Clinical Audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies. https://www.hqip.org.uk/national-programmes