NATIONAL CONGENITAL HEART DISEASE AUDIT (NCHDA)

2020 SUMMARY REPORT (2018/19 DATA)

NICOR

CONTENTS

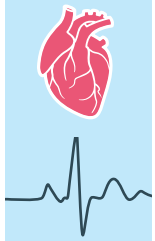
REPORT AT A GLANCE

Diagnosis

Congenital heart disease is diagnosed in 1:150 births (13 babies per day in the UK)*; about a third will require an intervention during infancy, often urgently.

Procedures

Most interventions are surgical but there has been a growth over the years of interventional and electrophysiology procedures, however with considerable variation in the ratio of these between congenital heart centres.



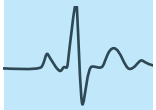
Procedure reporting

12064 procedures reported to the NCHDA in 2018/19, 8513 in children under 16.

Antenatal diagnosis

Antenatal diagnosis of conditions requiring intervention in infancy is at 50% overall, with high rates for patients with hypoplastic left heart syndrome and transposition of the great arteries with intact ventricular septum. For the first time we have analysed patients with tetralogy of Fallot & complete AVSD with encouraging results.

50%



Surgical procedures

Excellent outcomes with 98.6% survival rate for children under 16 undergoing surgical procedures.

98.6%

Data quality

There has been a gradual improvement in data quality in the audit over the years but 2 hospitals did not meet the desired standard for 2018/19.

x2

Consultants

1 in 10 surgical procedures overall (1 in 5 neonatal procedures) and approximately 1 in 3 transcatheter / electrophysiology procedures are now done with two consultants working together.

* https://www.bhf.org.uk/informationsupport/conditions/congenital-heart-disease

EXECUTIVE SUMMARY

Congenital heart disease (CHD) is a heart condition or defect that develops in the womb before a baby is born, with CHD diagnosed in approximately 1 in 150 births. Heart defects are the most common congenital anomaly in babies born in the UK and Ireland and they are the main cause of infant mortality due to a congenital anomaly. Today, at least 80% survive to adulthood and there are now more adults with CHD than children. Roughly one third of patients will require an intervention during infancy, often as a matter of urgency, with procedural risks highest for neonates who present in poor condition. A goal of congenital heart disease services is therefore to diagnose heart disease as early as possible and the ideal is before birth, referred to as antenatal diagnosis.

QUICK FACTS

- There were 12,064 congenital heart disease procedures on children and adults in 2018/19 (8,513 procedures on children under 16, accounting for 68% of all patients in the NCHDA in 2018/19).
- Overall survival rate for procedures on children under 16 is 98.6% in 2018/19, amongst the best reported worldwide.

KEY AUDIT FINDINGS

- Surgical Outcomes in Children: We continue to have excellent outcomes for under 16s undergoing cardiac surgery with the 30-day unadjusted post-surgical mortality rate at its lowest level, at 1.4% for 2018/19, outcomes that are amongst the best reported worldwide. Using PRAiS2 methodology, all 12 centres reported had survival rates for children under 16 years of age that were better than the lower alert and alarm limits.
- Procedure Outcomes in Adults: The 30-day post-surgical hospital-level aggregated survival rate using STAT procedure-linked risk-adjusted methodology for adults (16 years and over) was as predicted (no centre had a survival rate worse than the lower alert and alarm limits).
- Inter-centre Procedure Variability: This year we have analysed trends in countable surgical and transcatheter procedures in children (under 16 years) for the first time. The majority of procedures are surgical. There is considerable inter-centre variability (23-52%) but an overall growth over time in the proportion of catheter-based procedures.
- Antenatal Diagnosis: Antenatal diagnosis of congenital heart conditions for all infants requiring a procedure in the first year of life across the UK and Republic of Ireland remains at an overall 50% level. This year we have reported two new lesions – tetralogy of fallot (Fallot) and complete atrioventricular septal defect (complete AVSD) in addition to hypoplastic left heart syndrome (HLHS) and transposition of the great arteries with intact ventricular septum (TGA-IVS). While many individual hospitals are improving detections rates, there remains important variation between centres nationally. To address this, obstetric units should review staffing levels, the availability of quality sonography equipment and ensuring that sonography staff are receiving appropriate education and training.
- Dual consultant activity: Two or more consultants working together can deliver outcomes that could not be achieved by each working alone for the most complex lesions, or when unexpected complications occur. In addition, operating together is an important component of training and mentoring junior Consultant colleagues. The dual consultant operator data shows that one in ten surgical procedures and over a fifth of all neonatal surgical were undertaken by two consultant operators. One in three neonatal transcatheter or electrophysiology procedures also required dual consultant operators.
- Post-procedure complications: 30-day procedure related complication rates for under-16s show some variation in the incidence of each complication. However, the overall rate remains fairly constant when compared to last year. This includes 0.8% of cases requiring an emergency (surgery or transcatheter) procedure, 1.1% requiring an unplanned pacemaker, 1.2% having an adverse acute neurological event, 2.3% requiring life support, 4.7% with prolonged pleural drainage and 3.5% for those needing renal replacement therapy (dialysis).
- Data Quality Indicator (DQI): Although there has been a gradual increase in the number of centres with excellent scores over time, two hospitals did not reach the standard of >90% in 2018/19; seven were below 95%.

KEY RECOMMENDATION

- Hospitals should aim to increase the rate of antenatal diagnosis of conditions requiring intervention in the first year. Individual congenital heart disease networks should take responsibility for improving outcomes and play a pivotal role in reviewing staffing, infrastructure, education and training.

FUTURE PLANS

- The NCHDA plans to launch a new data tool, allowing centres to check their data completeness, to assess their performance against the key QI metrics and to allow them to set up local queries from the live database. This will allow more autonomous management of accuracy and completeness of hospital data on a continuous basis. This should help all centres achieve excellent data quality scores.

- The NCHDA will assess (and if necessary drive up) data quality required for additional metrics and include them in the audit to help institutions improve outcomes for their patients. This includes fluoroscopy times for procedures and unplanned operations and we will examine the requirements for providing longer-term (60/90-day) survival outcomes.

- The NCHDA will investigate further the issue of inter-centre variation in surgical and catheter-based procedures for specific conditions.

1. INTRODUCTION

The National Congenital Heart Disease Audit (NCHDA), a domain within the National Cardiac Audit Programme (NCAP), was set up in 2000 as the Central Cardiac Audit Database (CCAD for Congenital Heart Disease) to assess patient outcomes after therapeutic paediatric and congenital cardiovascular procedures (surgery, transcatheter and electrophysiological interventions) at all centres in the UK and the Republic of Ireland (since 2012). 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.

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). Data submission is mandatory and is collected from all centres undertaking such procedures in children and adults. It is the largest comprehensive national audit of its kind in the world, with over 140,000 patients (57% post-surgery) in the database undergoing over 208,000 procedures.

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.

Each year since the audit's inception, we have aimed to report key findings in a meaningful way to help inform and improve clinical practice and patient outcomes. To improve transparency, this report includes a summary for each Quality Improvement metric, which includes related National Standards and criteria underpinning the analysis. We also report a second year of post-procedure complications data as well as extending the longer-term trends from 10 to 11 years for this year only.

1.1 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 patient admission to hospital discharge. The required data items are routinely reviewed to reflect the changing needs of the congenital heart services 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?

1.2 THE SCOPE OF THE AUDIT

1.2.1 OVERVIEW OF QUALITY IMPROVEMENT METRICS

This report continues the strong focus of the NCAP and its six domains on identifying and communicating opportunities to raise the standards of care for patients. Data are used 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 and/or assessed quality of care are improved for patients or whether healthcare can be provided more efficiently.

This NCHDA domain summary relates to the following themes:

- **Safety** – how can services be made safer? This includes ascertaining the number of different types of procedures

undertaken by centres with respect to NHS England Standards, documenting trends in activity over the last 11 years. We also show when two consultants work together during a procedure and assess the quality and completeness of data submitted to the Audit for the financial year 2018/19.

- **Clinical effectiveness** – are the best clinical protocols and treatments being used? This focuses on the antenatal detection of CHD in patients who require a therapeutic procedure in infancy.

- **Patient outcomes** – how good are the outcomes for patients (mortality and post-procedural disorders) and how can we improve these? This includes overall aggregated and risk-adjusted 30-day mortality for children and adults, as well as after 83 specific procedures.

  Seven post-procedural specific disorders are also documented. The outcomes of centres undertaking CHD procedures are compared and those performing better or worse than expected are highlighted.

This summary focuses on these quality improvement themes and does not describe all the data available. The complete analyses, and audit methodology are available here.

1.2.2 ANALYTICAL SCOPE OF THE AUDIT

Congenital heart disease (CHD) 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 NCHDA results cover 3 different time periods:

- **1 year**: 2018/19 data collected from April 1st 2018 - 31st March 2019, which have not been reported on in any previous report.

- **3 years**: 2016/17 to 2018/19: is the standard reporting period for metrics related to the NCHDA in view of relatively small numbers of individual types of procedures.

- **11 years**: 2008/09 to 2018/19: expanded from recent 10 years trends, is used to demonstrate longer term variance as necessary.

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 NCHDA 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).

1.2.3 THE DATA QUALITY INDICATOR (DQI)

NCHDA validation includes a remote site validation process, which involves onsite assessment of data quality across 4 domains to produce a data quality indicator score for each centre assessed. The Data Quality Indicator score gives an indication of the quality of the data submitted by each mixed practice or paediatric centre against the expected NCHDA Standard shown in Table 1.

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 that 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. Further details about this process can be found in Appendix 1.

Table 1: *Summary of Data Quality Indicator*

QI Metric Description/Name	Data Quality Indicator (DQI) score.
Why is this important?	Data Quality Indicator score gives an indication of the quality of the data submitted by each centre against the expected NCHDA Standard
QI theme	Safety, Effectiveness, Outcomes
What is the standard to be met	Good quality = >90% Excellent quality = >98%
Key references to support the metric	Clarke DR, Breen LS, Jacobs ML, Franklin RC, Tobota Z, Maruszewski B, Jacobs JP. Verification of data in congenital cardiac surgery. Cardiol Young 2008; 18 suppl 2: 177-87[1]
Numerator	Variable and dependent upon complexity

QI Metric Description/Name	Data Quality Indicator (DQI) score.
Denominator	Dependent upon case-mix
Trends	Over the last few years, more centres have achieved excellent (>98%) standards (9/16 centres scored in 2018/19 compared to 4/18 in 2014/15).
Variance	Of the seven centres not achieving the excellent standard in 2018/19, two hospitals had a score of <90% and five others had scores between 90 and 95%.

Recommendation

Hospitals not achieving the desired data quality standard should improve data completeness and quality. This may require a review of staffing, IT infrastructure and level of engagement between local clinical leads and audit teams.

2. QUALITY IMPROVEMENT METRICS

2.1 SAFETY: CHD PROCEDURAL ACTIVITY

Table 2: *Summary of number of procedures/activity*

QI Metric Description/Name	Activity: • Procedural activity by age group and each centre • Catheter-based and surgical activity • Consultant activity
Why is this important?	Activity standards were set out by NHS England to provide the best opportunity of achieving good outcomes for cardiac procedures in children and adults with CHD.
QI theme	Safety
What are the standards to be met?	The NHS England Standards[2] require that: - a centre's CHD surgeons work in a team of at least 3-4 and are required to perform at least 125 CHD 'countable' operations (all ages), per year (the equivalent of about three a week), average over 3 years. - a centre's interventional cardiologists work in a team of at least 3-4 with the lead interventional cardiologist carrying out a minimum of 100 interventional procedures a year, and all other interventional cardiologists do a minimum of 50 interventional procedures a year, averaged over 3 years. This equates to each centre performing 200-250 interventional catheter cases each year. Note that the standards exclude purely diagnostic catheter procedures from these activity numbers.
Key references	• The Society for Cardiothoracic Surgery, supported by the community of congenital cardiac surgeons themselves, and by the Royal College of Surgeons. • Congenital Heart Disease Services: Decision Making Business Case November 2017: main document. https://www.england.nhs.uk/wp-content/uploads/2017/11/06-pb-30-11-2017-annex-b-chd-dmbc.pdf#page=28 [2] • Congenital Heart Disease Services: Decision Making Business Case November 2017: Annex B, page 358 (Appendix 1, Annex 6) https://www.england.nhs.uk/wp-content/uploads/2017/11/06-pb-30-11-2017-annex-b-chd-dmbc.pdf [3]
Numerator	NHSE countable surgical procedures - for neonate, child and adults.
Denominator	NHSE countable surgical procedures.
Trend	See Table 3 and Figures 1 and 2. Although surgical and catheter-based activity has increased from 2008/09, there was a 2% reduction in reported paediatric activity in 2018/19 compared to 2017/18. Surgical activity in patients 16 years and older grew from 2008/09 until 2013/14 but has gradually fallen since; similarly, there has been a gradual fall in transcatheter procedures for this group. In children, there has been a 7% fall in transcatheter procedures but a 4% increase in electrophysiology procedures between 2017/18 and 2018/19.
Variance	See Figure 3. Important inter-centre variability in the proportions of patients undergoing 'countable' surgical versus transcatheter interventions, and over this time period.

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 set out in NHS England's 2016 Standards and Services Specification.[2,3]

Although there remain no objective data to show the effect of implementing these recommendations across the country with respect to outcomes, 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). [4]

AUDIT FINDINGS

2.1.1 ALL PAEDIATRIC AND CHD PROCEDURES

In 2018/19, UK and Republic of Ireland centres submitted data on 12,064 procedures where 8,513 were paediatric cases and 3,557 were adult congenital heart cases as shown in Table 3 below.

A full breakdown of 30 day outcomes by age group for all procedures (2016/17 to 2018/19) as well as a breakdown of activity for centres undertaking major congenital cardiac procedures (2016/19) for children and adults in the UK can be found here.

Table 3: *CHD Activity by Age Group - All Procedures (2018/19)*

PROCEDURES 2018/19			
	Procedures (All ages)	Procedures (Under 16 years)	Procedures (16 years and older)
Overall activity	12,064	8,513	3,557
Surgical procedure activity			
Surgery undertaken using cardiopulmonary bypass	4,237	3,276	961
Surgery undertaken without using cardiopulmonary bypass (including surgical EP)	957	891	66
Hybrid procedures	74	66	8
Primary ECMO	64	62	2
Ventricular Assist Device (VAD)	32	31	1
Total	**5,362**	**4,326**	**961**
Catheter-based procedure activity			
Interventional catheterisation procedures	3,519	2,392	1,129
Diagnostic catheter procedures	1,634	1,045	592
Total	**5,153**	**3,437**	**1,721**
Electrophysiological activity (non-surgical)			
Implantable Cardioverter Defibrillator (ICD)	133	53	80
Pacemaker procedures	386	122	264
EP ablation and EP diagnostic procedures	1,029	575	454
Total	**1,549**	**713**	**792**

Note: Activity numbers are those procedures agreed by NHS England to be 'countable' towards individual operator activity, with the exception of diagnostic catheter procedures which are not currently considered 'countable'. Primary Extracorporeal Membranous Oxygenation (ECMO), Ventricular Assist Devices (VAD), lung transplants and surgical electrophysiological (EP) procedures are counted as surgical activity for these calculations. Hybrid procedures are those with a combination of surgical and transluminal catheter interventions undertaken at the same time in the operating theatre. Primary ECMO procedures are when this procedure is undertaken in isolation and not as a support operation after another congenital heart procedure (these latter are considered post-procedural complications).

Table 4: *Total number of cases categorised by type of procedure submitted to the NCHDA financial years (2008/09 to 2018/19)*

Year	Surgical	Hybrid	Interventional catheter & EP procedures			Diagnostic Catheter	Total
			EP/PACING	ICD	Intervention		
2008/09	4,973	12	528	47	3,328	—	8,888
2009/10	5,302	6	443	31	3,468	—	9,250
2010/11	5,902	6	627	64	3,741	—	10,340
2011/12	5,781	26	692	72	3,806	—	10,377
2012/13	5,909	16	777	84	3,617	—	10,403
2013/14	6,018	49	938	108	3,697	—	10,810
2014/15	5,656	62	1,031	116	3,435	—	10,300
2015/16	5,671	55	1,344	124	3,614	1,737	12,545
2016/17	5,677	48	1,457	155	3,837	1,879	13,053
2017/18	5,376	80	1,440	112	3,673	1,745	12,426
2018/19*	5,288	74	1,416	133	3,519	1,634	12,064
Total	**61,553**	**434**	**10,693**	**1,046**	**39,735**	**6,995**	**120,456**

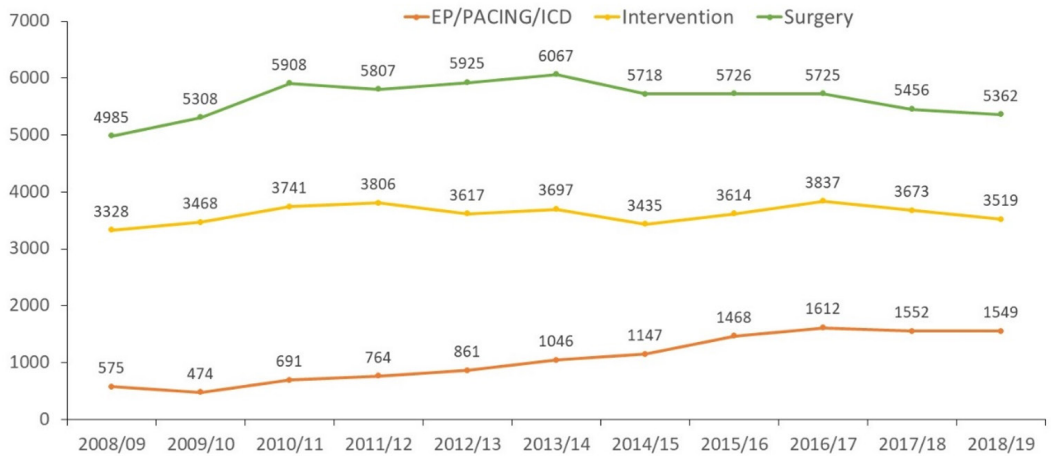
Note: Primary Extracorporeal Membranous Oxygenation (ECMO), Ventricular Assist Devices (VAD) and lung transplants are counted as surgical activity for these calculations; interventional, Electrophysiology (EP)/Pacing and Implantable cardioverter-defibrillator (ICD) devices are counted as catheter procedures, and were not collated separately until 2013/14. 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.

** Note that 1 centre (Harley Street Clinic) did not submit data this year accounting for approximately 130 procedures (approximately 80 fewer surgical procedures, 30 fewer catheter interventions, 10 fewer EP and 10 fewer diagnostic catheters).*

Table 4 and Figures 1 and 2 show eleven-year trends for CHD procedures, split by procedure type and divided into four age groups. Surgical activity over the last five years has slightly fallen in the UK and Republic of Ireland, with up to a 2% reduction in paediatric activity in 2018/19 (noting no data from one small centre in 2018/19). This slight negative trend has been most marked in the neonatal age group. This may reflect the known 10% drop in the birth rate in England and Wales from its peak in 2012[5] combined with a trend to perform more transcatheter interventions in neonates and infants, such as patent arterial duct closure in premature babies, and procedures to increase pulmonary blood flow by stenting open the arterial duct or right ventricular outflow tract in individuals with cyanotic CHD.

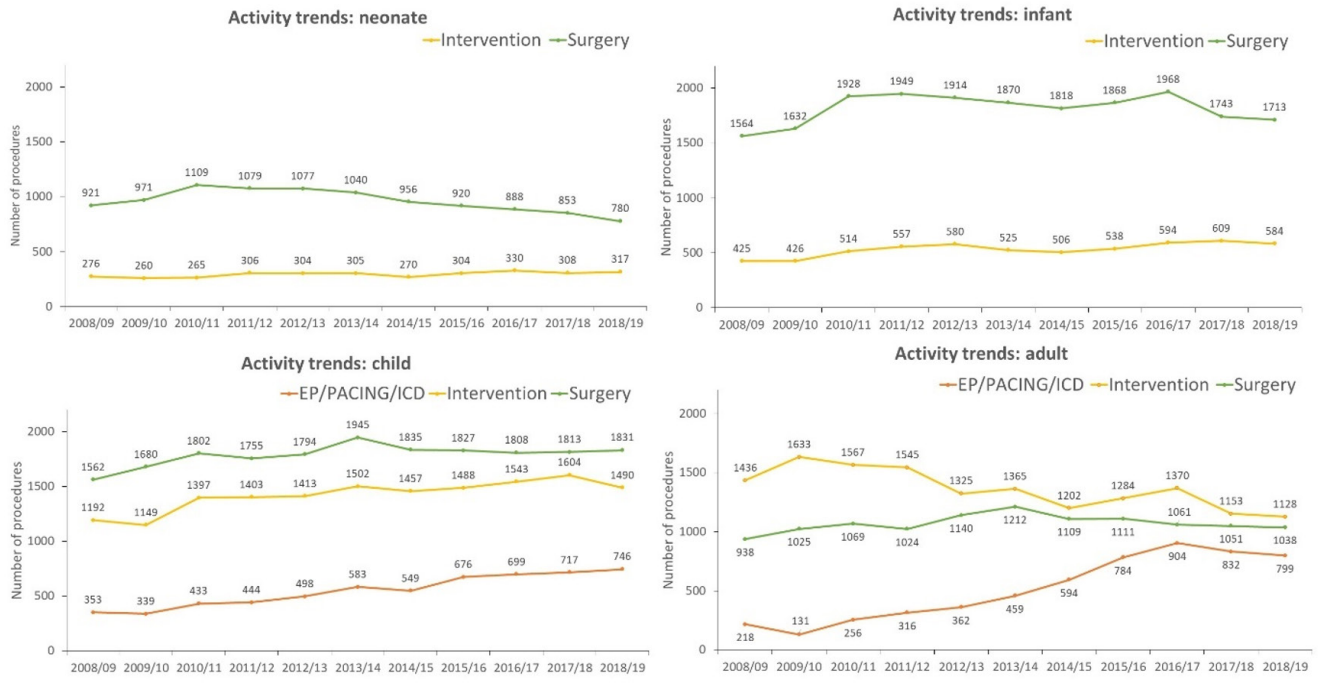
Although there was a gradual increase in surgical procedures for patients 16 years and older between 2008/09 and 2013/14, there has been a gradual fall since. There has also been a gradual fall in transcatheter procedures in adults since 2009/10. Although there has been an overall increase in catheter-based procedures since 2008/09, there was a 4% fall in transcatheter activity compared to 2017/18. The overall number of electrophysiology procedures has been static for a few years, although there has been a 5% increase in procedures on children between 2017/18 and 2018/19 but a simultaneous fall in such procedures in older patients. The overall increase in electrophysiological activity in adults over the last 10 years may in part be due to better case ascertainment as all patients born with CHD who have rhythm problems in adulthood are comprehensively entered into the NCHDA database, rather than only in the NICOR National Cardiac Rhythm Management Audit. NICOR plans to enable cross linkage of data between the different domains within NICOR to avoid the need for dual data entry in the future.

Figure 1: *11-year trends of surgical, interventional catheter and electrophysiological procedures at all ages submitted to the NCHDA (financial years 2008/09 to 2018/19)*



Note: for details of procedural inclusions and exclusions, see Table 3.
2008 = financial year 2008/09, etc.

Figure 2: *11-year trends of surgical, interventional catheter and electrophysiological procedures split into four age groups submitted to the NCHDA (financial years 2008/09 to 2018/19)*



Note: for details of procedural inclusions and exclusions, see Table 2. Diagnostic catheter procedures are not included in these calculations. The number of electrophysiological procedures in neonates and infants is relatively low and hence this trend is not shown for these age groups.

Figure 3 (a & b) shows the 11-year trend at centre level for catheter-based interventions vs surgical procedures in the paediatric population. Though the majority of centres show a relative proportion between 40-60%, there is important inter-centre variability emerging in the proportions of patients undergoing 'countable' transcatheter versus surgical interventions over the time period as well as the growth in proportion of catheter-based procedures. Further analysis by specific diagnosis is warranted to better understand this variation.

Figure 3a: *Ratio of interventional catheter vs surgical procedures illustrating 11-year temporal trend in those less than 16 years old (2008/09 to 2018/19)*

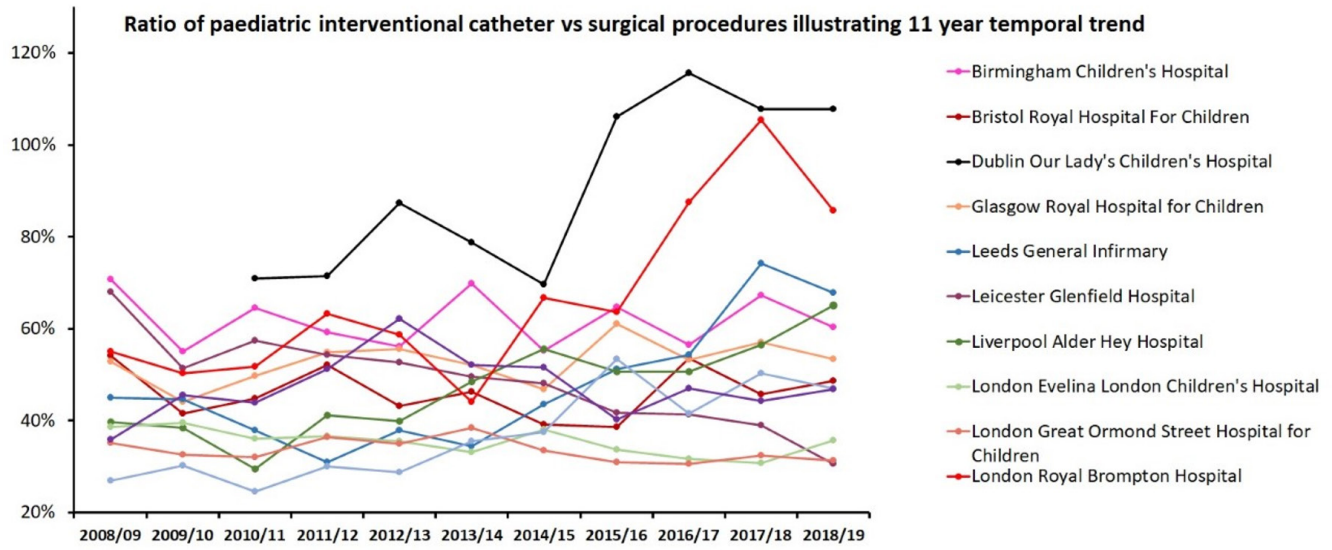
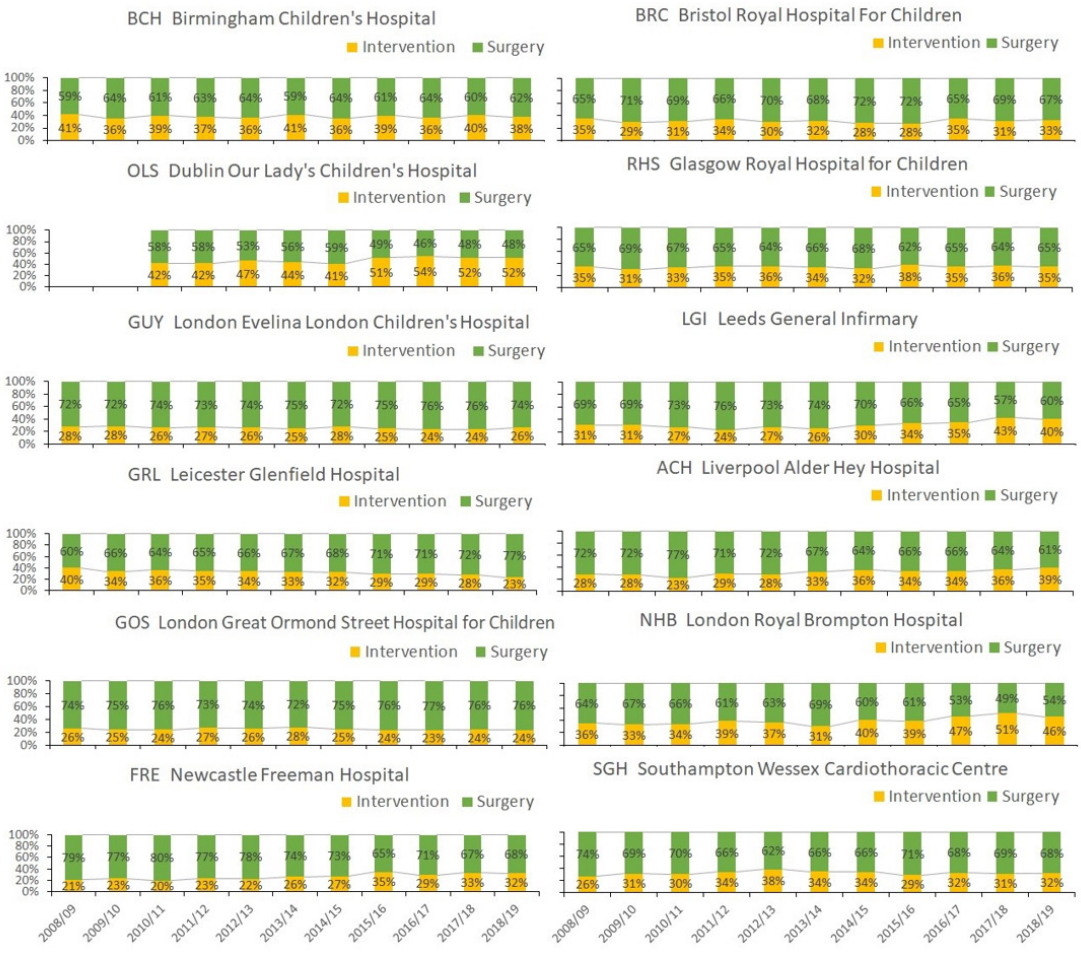


Figure 3b: *11-year temporal trend of proportions of surgical vs interventional catheter procedure in under 16-year olds, shown by each centre (2008/09 to 2018/19)*



2.1.2 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 as shown in Table 2.[2,3,6] A key NHS England Standard, supported by the Society of Cardiothoracic Surgeons, 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).[7]

The exact nature of the procedure undertaken is also important for the standards and these 'countable procedures' were delineated by an NHS England-led subcommittee of congenital heart disease specialists in 2017.[2] Relatively minor operations, purely diagnostic catheter procedures and mechanical life support therapy used after CHD procedures are excluded. When calculating the number of procedures an individual consultant operator undertakes, there is a need to consider the scenario when there are two consultants scrubbed for the same patient (excluding a consultant scrubbing with a non-consultant trainee) as depicted in Table 5a and 5b.

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.

The NCHDA dataset is now able to capture these three scenarios but will not be able to report the results for at least another year.

Table 5a: *Total number of surgical cases submitted to the NCHDA categorised by type of procedure and age group (financial years 2016/17 to 2018/19), illustrating the number of cases with two consultants operating at the same session*

Hospital Surgery (overall)	All ages - dual/total		Neonates		Infant		Child		Adult	
	1823 / 16548	11%	348 / 2386	15%	525 / 5563	9%	5453	10%	3146	12%
Bypass	1508 / 13033	12%	272 / 1468	19%	406 / 4093	10%	4545	11%	2937	12%
Non-bypass	124 / 3030	4%	39 / 787	5%	46 / 1343	3%	704	4%	196	7%
Hybrid	160 / 202	79%	34 / 44	77%	68 / 85	80%	57	77%	16	88%
Primary ECMO	11 / 204	5%	2 / 86	2%	3 / 34	9%	81	6%	3	33%
Ventricular Assist Device (VAD)	20 / 79	25%	1 / 1	100%	2 / 8	25%	66	23%	4	50%

Table 5b: *Total number of Catheter/Electrophysiology cases submitted to the NCHDA categorised by type of procedure and age group (financial years 2016/17 to 2018/19), illustrating the number of cases with two consultants operating at the same session*

Hospital Catheter / Electrophysiology (overall)	All ages - dual/total		Neonates		Infant		Child		Adult	
	4342 / 21008	21%	304 / 1012	30%	557 / 2726	20%	1472 / 9199	16%	2009 / 8071	25%
Interventional	3088 / 11035	28%	280 / 895	31%	466 / 1847	25%	894 / 4639	19%	1448 / 3654	40%
Implantable Cardioverter Defibrillator (ICD)	53 / 400	13%	0 / 0	0%	1 / 3	33%	28 / 131	21%	24 / 266	9%
Pacemaker procedures	100 / 1187	8%	0 / 1	0%	0 / 4	0%	49 / 358	14%	51 / 824	6%
EP & ablation & diagnostic EP	526 / 3125	17%	0 / 0	0%	1 / 9	11%	315 / 1672	19%	2101444	15%

Diagnostic catheter	575 / 5261	11%	24 / 116	21%	89 / 863	10%	186 / 2399	8%	276 / 1883	15%

Figure 4: *Bar chart showing the percentage of patients of any age who had their procedure undertaken by two consultant operators, broken down by procedure type (financial years 2016/17 to 2018/19)*

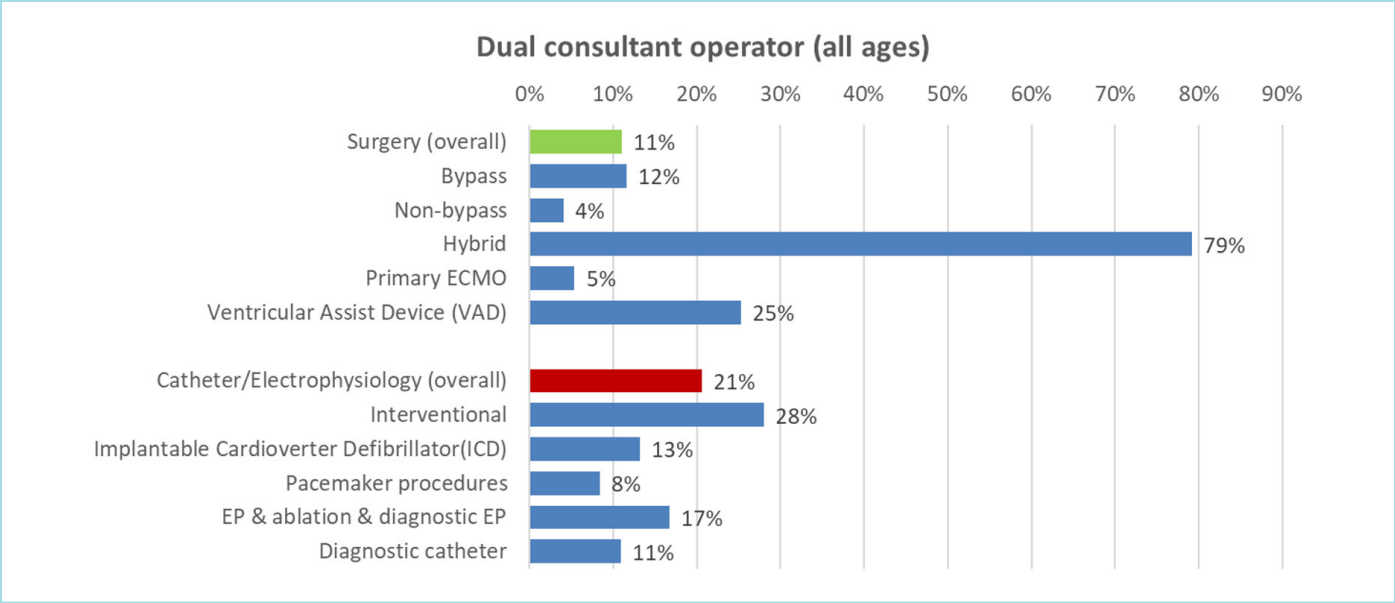
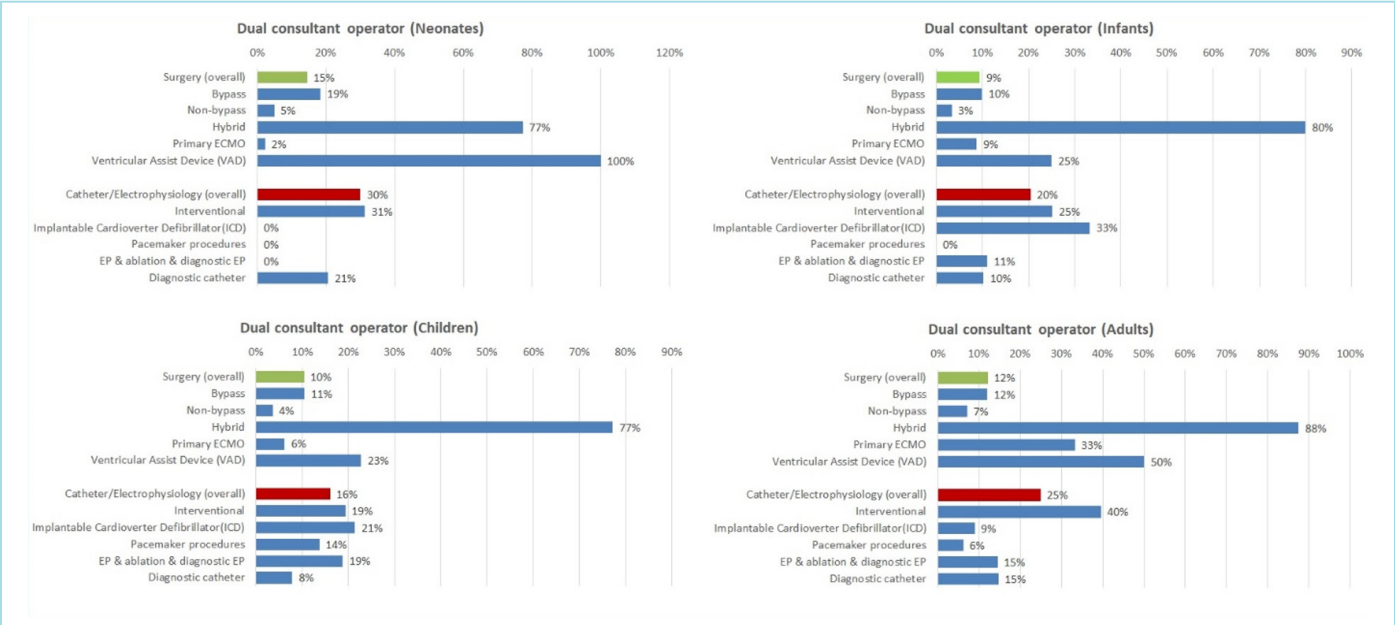


Figure 5: *Bar charts showing the percentage of patients who had their procedure undertaken by two consultant operators, broken down by procedure type and age bracket (financial years 2016/17 to 2018/19)*



For 2016/17 to 2018/19, the dual consultant operator data show that over a fifth of all neonatal surgical and around a third of neonatal transcatheter interventions were undertaken by two consultant operators, whilst this is the case in 10% of older children and adults having surgery [Figures 4 & 5]. In contrast, over a third of transcatheter interventions in adults have dual consultant operators, probably attributable to the number of transcatheter valve implants undertaken. These results are similar to last year.

Figure 5 shows again that dual consultant operators for hybrid procedures for all age groups is still below the expected 100% (around 80%). Hybrid procedures require input by both a consultant surgeon and consultant catheter interventionist due to case or procedure complexity, such as atypical coronary anatomy when undertaking an arterial switch procedure, or with transcatheter valve implantation. The reason for this discrepancy is likely to be a data entry error: either the procedure has been misclassified as hybrid or the procedure did not involve a consultant cardiologist but rather just a highly trained junior doctor. Going forwards the NCHDA will ensure this discrepancy is addressed by the centres at the time of data entry, such that the software brings up an alert in this scenario.

The NHS England review concluded that not all English centres treating children and adults fully met the current requirements. Hospitals undertaking congenital cardiac surgery were recommended to continue to work with specialist commissioners and to aim to meet the NHS England Standards.[7] The original plan for this to be reviewed again in two years' time, is likely to be stalled given the ongoing COVID-19 pandemic, which has severely affected the ability to undertake elective CHD procedures across all age groups.

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 undertook peer review visits to all centres involved in tertiary level congenital heart services for children in England, Scotland and Wales during 2019. This report, although complete, has not yet been published by NHS England.

A series of Qualitative Indicators have been developed to assess compliance with the CHD service standards[7] 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).

2.2 EFFECTIVENESS: ANTENATAL DIAGNOSIS

Table 6: *Summary of level of antenatal diagnosis*

QI Metric Description/Name	**Antenatal diagnosis of CHD in those requiring a procedure in infancy - overall and 4 specific diagnoses:** • **Hypoplastic left heart syndrome (HLHS)** • **Transposition of the great arteries with intact ventricular septum (TGA-IVS)** • **Tetralogy of Fallot (TOF)** • **Complete atrioventricular septal defect (cAVSD)**
Why is this important?	Antenatal diagnosis improves postnatal survival and morbidity after neonatal procedures. It also gives opportunities for parental counselling about the likely outcomes for their babies, investigations for associated extracardiac and genetic anomalies, and prenatal planning for the optimal place and method of delivery, as well as management in the perinatal period.
QI theme	Effectiveness and timeliness
What are the standards to be met?	National fetal cardiology group recommendation for sonographers to: 1. Achieve an antenatal diagnosis rate of at least 75% for all abnormalities where an intervention is undertaken in the first year of life; 2. Achieve a high antenatal diagnostic rate of at least 90% for certain specific lesions where an intervention within hours of birth may be required.
Key references	• Gardiner HM, Kovacevic A, van der Heijden LB, et al. Prenatal screening for major congenital heart disease: assessing performance by combining national cardiac audit with maternity data. Heart. 2014 Mar; 100(5):375-82.[8] • Holland BJ, Myers JA, Woods CR. Prenatal diagnosis of critical congenital heart disease reduces risk of death from cardiovascular compromise prior to planned neonatal cardiac surgery: a meta-analysis. Ultrasound Obstet Gynecol 2015;45:631–8.[9]
Numerator	Those with CHD who have an antenatal diagnosis and have had a countable procedure in infancy.
Denominator	Number of infants with CHD who underwent a therapeutic procedure in the first year of life, excluding patent arterial ductal and atrial septal defect closure procedures.
Trend	Ongoing improvement in antenatal diagnostic rates for infants requiring a cardiovascular procedure over the last 11 years across the UK and Republic of Ireland, as well as regional levels in England and Wales. However, the overall rate in 2018/19 (50%) has not improved substantially compared with the result in 2017/18 and is below the target.
Variance	Considerable regional variation remains between centres and their diagnostic success rate of CHD in those requiring a procedure in infancy.

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.[8] A goal of CHD 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.[9]

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. This means that fetal cardiologists and the tertiary congenital cardiology centres listed in this report, do not have direct management of the obstetric sonographer team who undertake screening for CHD. 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.[10]

It is the NHS Fetal Anomaly Screening Programme that mandates the fetal echocardiographic views that sonographers use during screening. Originally this was simply the four chamber view and this was then expanded to left and right ventricular outflow tract (great arterial) views for detection of additional malformations such as transposition of the great arteries.[11] Most recently the three vessel and trachea views have been introduced as an aid to detect great arterial distal anomalies and disproportion.[11] Given this history, it is not surprising that 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 a highly abnormal four chamber view.[12] Many important congenital heart malformations with great arterial abnormalities may have an entirely normal four chamber view and are therefore more difficult for the sonographers performing the screening scans to detect.

It is very important to emphasise that the NCHDA only publishes the success rate of antenatal detection of CHD by sonographers in those children who have survived pregnancy and have then required a procedure in infancy. These antenatal diagnosis rates of important CHD, in that they have required a procedure in infancy, are inevitably an underestimate of national and local prenatal detection success as they do not take into account the four other possible outcomes following a fetal cardiac diagnosis:

- fetal death (spontaneous or termination of pregnancy)
- perinatal or postnatal death before an otherwise planned procedure was possible
- less severe malformations that have not required a procedure in infancy
- when a decision was made not to intervene on the infant due to the complexity of the heart abnormality or associated comorbidities such as severe chromosomal anomalies (compassionate care).

Of note, is that the specific lesions the NCHDA has focussed on would all expect to have procedures when a neonate or in infancy, unless designated for compassionate care. A further unknown factor is the likely small number of women who decide against antenatal sonographic screening for cultural and-or religious reasons – antenatal screening is not mandatory.

We therefore do not yet know the true proportion of children with CHD who are diagnosed antenatally. NICOR has been working with Public Health England and the National Congenital Anomaly and Rare Disease Registration Service (NCARDS) to develop better measures to establish this, as well as developing an extension to the NCHDA dataset to include all those who have an antenatal diagnosis of CHD whatever their later outcome. It is hoped that direct linkage between the NCHDA database and NCARDS data would provide a comprehensive database to track diagnosis-based outcomes of all patients born with CHD, not just individuals who require a cardiovascular procedure.

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 a high antenatal diagnostic rate of at least 90% for certain specific lesions where an intervention within hours of birth may be required. To this end we have collated and published data for two such malformations based on these diagnoses within the NCHDA database and not dependent on which postnatal procedure they may have had:
  - hypoplastic left heart syndrome (HLHS), as a type of functionally univentricular heart
  - transposition of the great arteries with intact ventricular septum (TGA-IVS), as an example of a major malformation of the great arteries.

In both conditions, infants may need an emergency balloon atrial septostomy procedure within hours of delivery and all would normally undergo major neonatal surgery usually within the first week of life, if not born prematurely. Research has shown that an antenatal diagnosis improves survival with fewer complications and better neurocognitive outcomes.[13,14] Prenatal detection will also 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.

This year we have added two more lesions with the ongoing aim of highlighting the importance of early diagnosis of a range of complex congenital heart malformations:

- tetralogy of Fallot (Fallot), as an example of large intra-cardiac shunt and narrowing of the pulmonary outflow tract supplying blood to the lungs, whose detection is dependent on the sonographer seeing an abnormal great vessel view. The four-chamber view in this case is most often normal.
- complete atrioventricular septal defect (complete AVSD), as a type of large intra-cardiac shunt, often associated with trisomy 21. In this case the four-chamber view is usually abnormal and key to the diagnosis.

However, in these cases this initial categorisation was based not on the diagnosis itself but on the Specific Procedure used most frequently to definitively repair the lesion, namely repair of tetralogy of Fallot and repair of complete AVSD. We plan to refine this approach to better capture all such patients for the next NCHDA report.

AUDIT FINDINGS

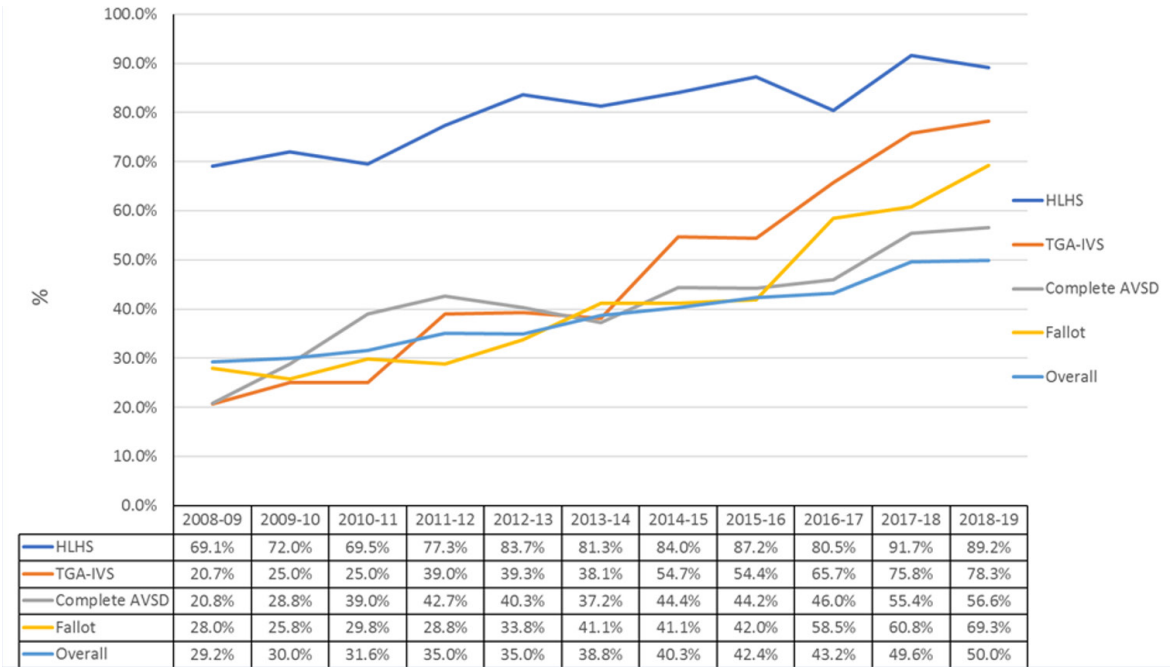
2.2.1 OVERALL DETECTION OF INFANTS REQUIRING A PROCEDURE

The latest audit data for 2018/19 show a continuing positive trend in antenatal detection rates of all infants requiring a procedure with a successful antenatal detection [Table 7 and Figure 6]. Of note, is that the methodology was tightened this year to ensure that patients were not counted more than once by ensuring that if an interunit transfer was made from one centre to another, that the infant was only counted once in terms of antenatal detection. There were 146 such cases. In addition, rules about excluding any patients who had an isolated arterial duct procedure and were miscoded as having had an antenatal diagnosis were also excluded. These changes may partially explain the lower percentage increase seen than hoped for in comparison to previous years.

Table 7: *11-year trend of proportion of patients undergoing procedures in infancy successfully diagnosed antenatally (financial years 2008/09 to 2018/19) in the UK and Republic of Ireland*

Overall Diagnosis in 2008-2019			
Financial Year	**Overall diagnosis**	**Total**	**% Antenatally diagnosed**
2008/09	517	1,770	29.2%
2009/10	560	1,869	30.0%
2010/11	680	2,154	31.6%
2011/12	737	2,106	35.0%
2012/13	780	2,230	35.0%
2013/14	843	2,175	38.8%
2014/15	852	2,114	40.3%
2015/16	915	2,159	42.4%
2016/17	953	2,208	43.2%
2017/18	1,029	2,075	49.6%
2018/19	1,011	2,024	50.0%
Total	**8,877**	**22,884**	**38.8%**

Figure 6: *11-year temporal trend in proportion of infants who underwent a procedure and were diagnosed antenatally (financial years 2008/09 to 2018/19)*



	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19
HLHS	69.1%	72.0%	69.5%	77.3%	83.7%	81.3%	84.0%	87.2%	80.5%	91.7%	89.2%
TGA-IVS	20.7%	25.0%	25.0%	39.0%	39.3%	38.1%	54.7%	54.4%	65.7%	75.8%	78.3%
Complete AVSD	20.8%	28.8%	39.0%	42.7%	40.3%	37.2%	44.4%	44.2%	46.0%	55.4%	56.6%
Fallot	28.0%	25.8%	29.8%	28.8%	33.8%	41.1%	41.1%	42.0%	58.5%	60.8%	69.3%
Overall	29.2%	30.0%	31.6%	35.0%	35.0%	38.8%	40.3%	42.4%	43.2%	49.6%	50.0%

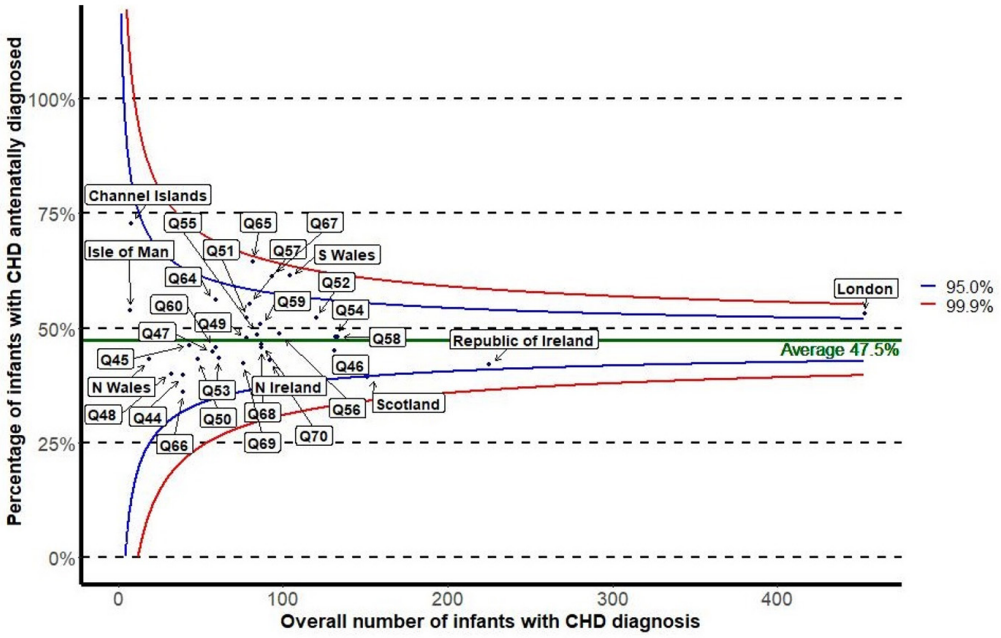
Overall = any cardiac malformation; HLHS = hypoplastic left heart syndrome; TGA-IVS = transposition of great arteries with intact ventricular septum; Complete AVSD = complete atrioventricular septal defect; Fallot = tetralogy of Fallot.

Overall, there was an overall mean detection rate of 50% in 2018/19 for all infants requiring a procedure in the first year of life. The mean rate for the 2016/17 to 2018/19 period was 47.5%. [Table 7, Figure 7]. Despite this encouraging upward trend, there remains considerable regional variation in diagnostic rates for congenital heart disease before birth as shown in Table 8 with some regions in 2018/19 achieving well over 60% (Bristol, North Somerset, Somerset and South Gloucestershire (Q65)) and two areas of South Wales (7A3, 7A6), whilst others remain below 40% (Merseyside (Q48), Hertfordshire & South Midlands (Q58), Devon and Cornwall (Q66) and Thames Valley (Q69)). The funnel plots below and on-line maps show graphically the regions where additional training for obstetric sonographers may be best targeted and which centres are performing best, given the caveats above that only continuing pregnancies are included of babies who have required an intervention in infancy.

There are evidently a large number of regions who have scope for considerable improvement in detection rates. However, of importance is that most regions have many local screening centres sited within them, especially highly populated ones, such as the Thames Valley and London, with likely important centre-level variation in diagnostic rates within a region. Going forwards the NCHDA is planning to move away from regional reporting in England to reporting antenatal detection rates along the geographic boundaries of Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs). 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.

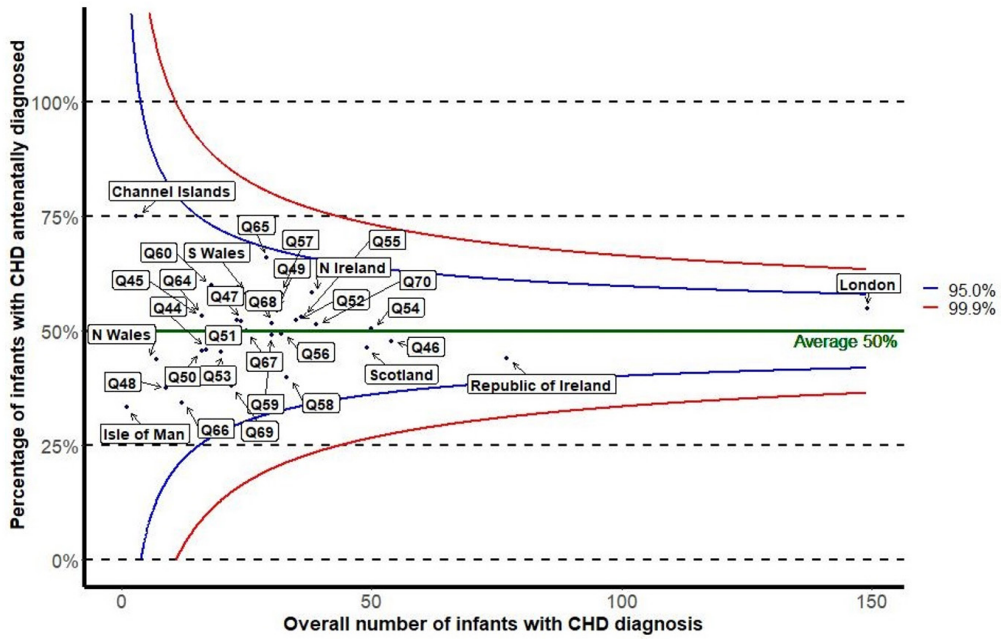
Figures 7a & b: Funnel plots showing the overall antenatal detection rates by region, 2016/17 to 2018/19 (upper panel) and 2018/19 (lower panel), for infants who underwent a procedure

Figure 7a: *Overall antenatal detection rates by region (2016/17 to 2018/19)*



See Table 8 for key to numbered regions.

Figure 7b: *Overall antenatal detection rates by region (2018/19)*



See Table 8 for key to numbered regions.

Table 8: *Regional and national antenatal diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2018/19 in the UK and RoI*

Overall Diagnosis in 2008-2019			
LAT	**Overall diagnosis**	**Total**	**% Antenatally diagnosed**
Channel Islands	3	4	75%
England	811	1612	50.3%
Isle of Man	1	3	33.3%
Northern Island	38	65	58.5%
Republic of Ireland	77	175	44.0%
Scotland	49	106	46.2%
Wales	32	59	54.2%
Q44. Cheshire, Warrington and Wirral	17	37	45.9%
Q45. Durham, Darlington and Tees	16	30	53.3%
Q46. Greater Manchester	54	113	47.8%
Q47. Lancashire	24	46	52.2%
Q48. Merseyside	9	24	37.5%
Q49. Cumbria, Northumberland, Tyne and Wear	31	57	54.4%
Q50. North Yorkshire and Humber	16	35	45.7%
Q51. South Yorkshire and Bassetlaw	23	44	52.3%
Q52. West Yorkshire	35	67	52.2%
Q53. Arden, Herefordshire and Worcestershire	20	44	45.5%
Q54. Birmingham and the Black Country	50	99	50.5%
Q55. Derbyshire and Nottinghamshire	36	68	52.9%
Q56. East Anglia	32	65	49.2%
Q57. Essex	32	55	58.2%
Q58. Hertfordshire and the South Midlands	33	83	39.8%
Q59. Leicestershire and Lincolnshire	30	61	49.2%
Q60. Shropshire and Staffordshire	18	30	60.0%
Q64. Bath, Gloucestershire, Swindon and Wiltshire	16	30	53.3%
Q65. Bristol, North Somerset, Somerset and South Gloucestershire	29	44	65.9%
Q66. Devon, Cornwall and Isles of Scilly	12	35	34.3%
Q67. Kent and Medway	25	50	50.0%
Q68. Surrey and Sussex	30	58	51.7%
Q69. Thames Valley	22	58	37.9%
Q70. Wessex	39	76	51.3%
Q71. London	149	272	54.8%
North Wales	7	16	43.8%
South Wales	25	43	58.1%
Local Health Board 7A2	0	4	0.0%
Local Health Board 7A3	12	13	92.3%
Local Health Board 7A4	4	9	44.4%
Local Health Board 7A5	3	8	37.5%
Local Health Board 7A6	6	9	66.7%

Overall Diagnosis in 2008-2019			
LAT	**Overall diagnosis**	**Total**	**% Antenatally diagnosed**
Overseas	10	27	37.0%
Unknown	3	4	75.0%
Total	**1011**	**2024**	**50.0%**

RoI = Republic of Ireland

2.2.2 DETECTION RATES FOR INDIVIDUAL CARDIAC MALFORMATIONS

Figure 8 and Table 9 show the expected continued high diagnosis rate for hypoplastic left heart syndrome, rising from about 70% 11 years ago to around 90% in the last two years. 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 21% in 2008/09 to over 78% in 2018/19. There have also been similar increases over time for complete AVSD, rising from 21% in 2008/09 to 57% in 2018/19, and tetralogy of Fallot from 28% in 2008/09 to 69% in 2018/19. It is important to note that the NCHDA rates for tetralogy of Fallot and complete AVSD do not include infants who may have had a palliative initial procedure, such as systemic-to-arterial shunt or transcatheter stent in the arterial duct or right ventricular outflow tract for tetralogy of Fallot or banding of the pulmonary trunk for complete AVSD and who then had definitive surgery at over one year age (a small minority of cases). The NCHDA will be modifying this analysis for the next report to take this into account. Further, complete AVSD is characterised by a spectrum of disease with varying sizes of holes between the chambers. Those with small interventricular communications are least likely to be detected antenatally; perhaps partially explaining why antenatal diagnostic rates are relatively low for this lesion.

Table 9: *11-year detection rates for HLHS, TGA-IVS, complete AVSD and tetralogy of Fallot antenatally diagnosed and who underwent a procedure within 12 months of birth (2008/9 to 2018/19)**

Financial Year	HLHS		TGA-IVS		Complete AVSD		Tetralogy of Fallot	
	N	%	N	%	N	%	N	%
2008/09	56	69.1%	17	20.7%	21	20.8%	45	28.0%
2009/10	72	72.0%	20	25.0%	34	28.8%	41	25.8%
2010/11	66	69.5%	25	25.0%	57	39.0%	62	29.8%
2011/12	75	77.3%	30	39.0%	70	42.7%	57	28.8%
2012/13	82	83.7%	33	39.3%	58	40.3%	77	33.8%
2013/14	87	81.3%	32	38.1%	54	37.2%	102	41.1%
2014/15	79	84.0%	41	54.7%	63	44.4%	95	41.1%
2015/16	82	87.2%	49	54.4%	65	44.2%	94	42.0%
2016/17	66	80.5%	46	65.7%	74	46.0%	152	58.5%
2017/18	77	91.7%	50	75.8%	72	55.4%	160	60.8%
2018/19	66	89.2%	54	78.3%	73	56.6%	124	69.3%

** Full table for individual lesions available here*

In one recent (2017) report from Paris, the diagnostic rates for functionally single ventricle, transposition of the great arteries and tetralogy of Fallot being 95%, 71% and 68% respectively.[15] However, this report includes those families who opted not to continue the pregnancy, and also was not dependent on whether a postnatal procedure was required (all fetal outcomes were included: termination, in utero demise and live born with or without a procedure in infancy). Termination rates in Paris were 70%, 3% and 12% respectively for the above lesions. Given the high rates of ante-natal detection associated with such decisions, the UK and Ireland detection rates for those live born and requiring a procedure in infancy appear to compare well. However, this is speculative particularly as it is known that termination rates are non-uniform across the UK and Ireland due to religious, cultural and socio-economic factors, and these should be borne in mind when interpreting the NHCDA regional data in this report.

Figures 8 (a,b,c and d): Funnel plots showing the antenatal detection rates by region for the three years 2016/17 to 2018/19 for four CHD conditions for those who underwent a cardiovascular procedure in the first year of life

Hypoplastic left heart syndrome, transposition of great arteries with intact ventricular septum, tetralogy of Fallot and complete atrioventricular septal defect (complete AVSD).

Figure 8a: *Hypoplastic left heart syndrome*

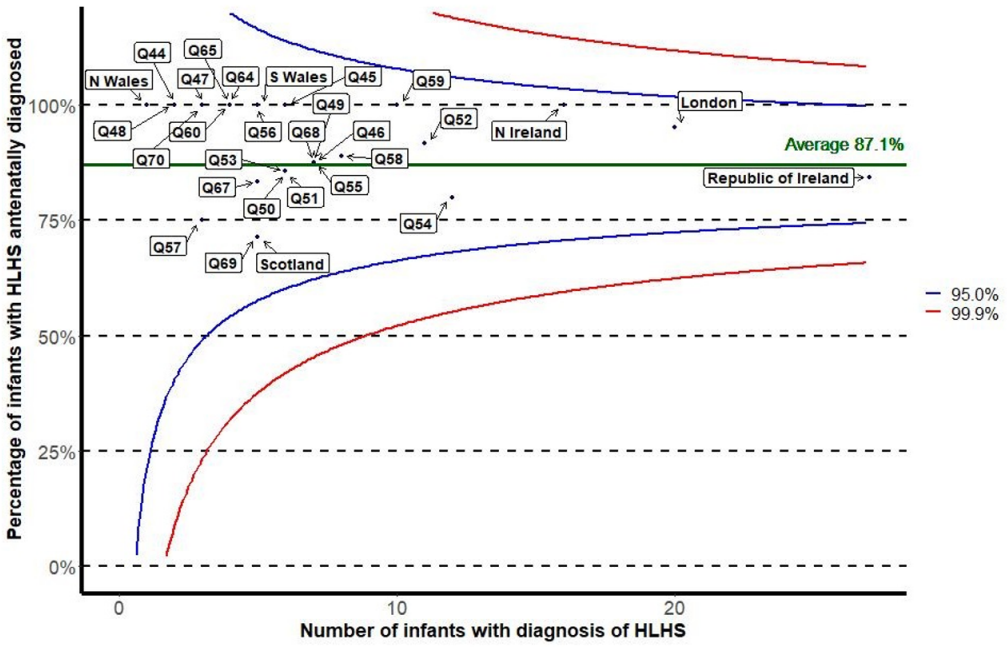


Figure 8b: *Transposition of great arteries with intact ventricular septum*

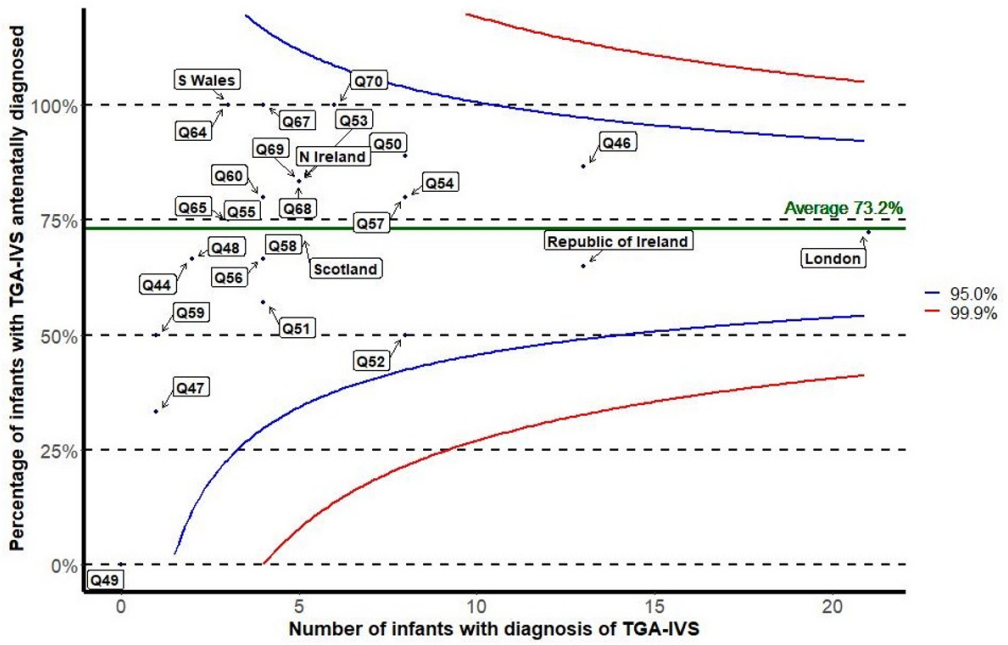


Figure 8c: *Tetralogy of Fallot*

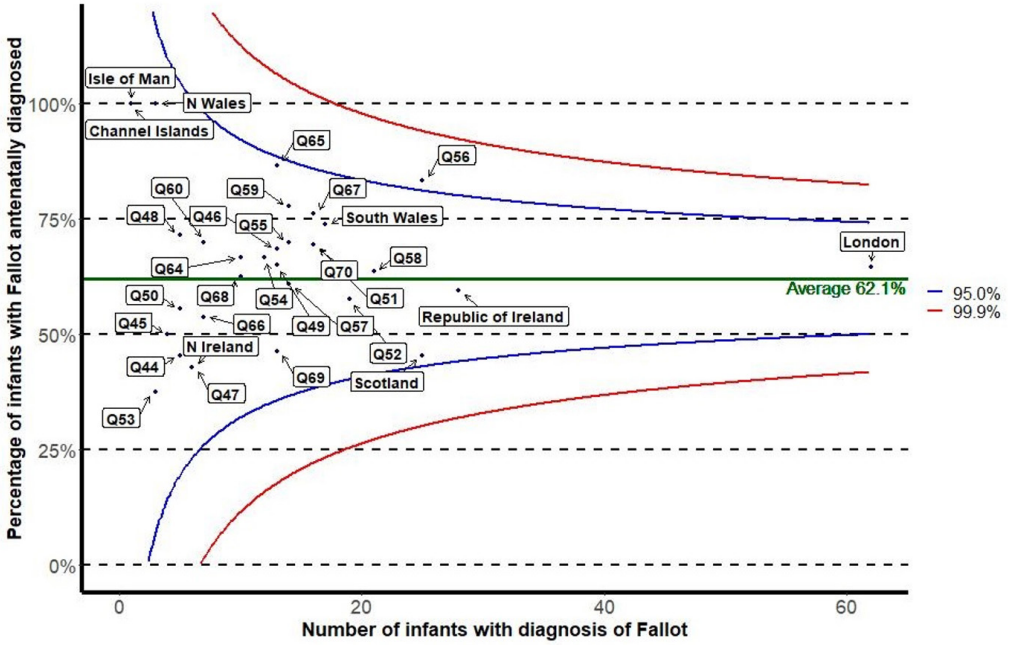
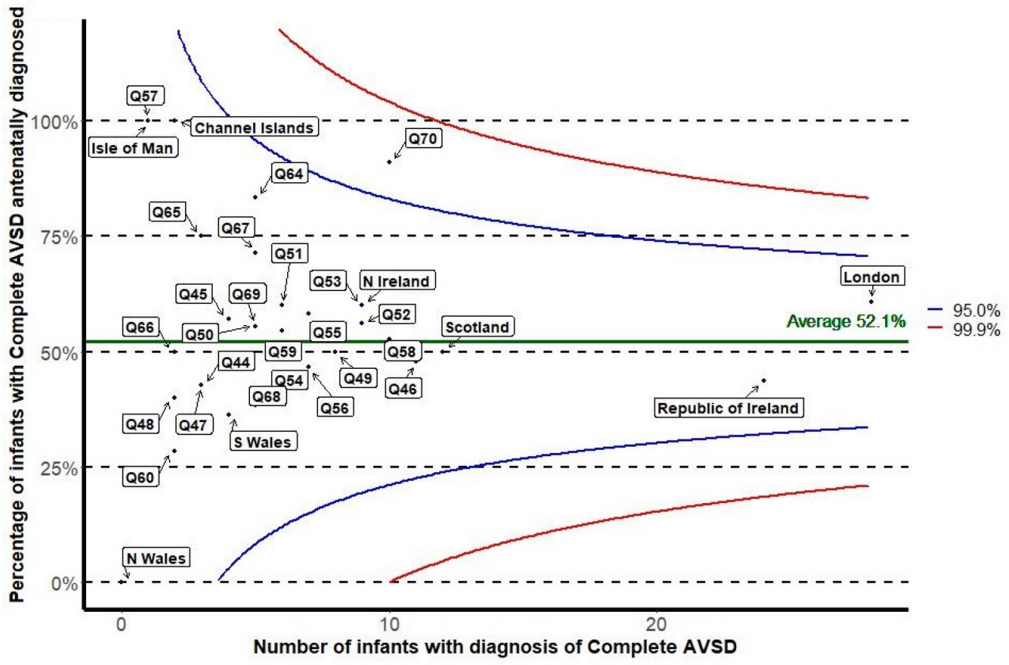


Figure 8d: *Complete atrioventricular septal defect (complete AVSD)*



Antenatal diagnosis is likely to have had an important influence on 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, there remain considerable differences [Table 10, Figure 8b], with only 50% detection in some regions for transposition of the great arteries compared to up to 100% in others [Table 10]. This and the detection rates for tetralogy of Fallot [Figure 8c] suggest that these and likely, other great arterial malformations, remain challenging diagnoses for many centres. Similar variance can be seen for complete atrioventricular septal defect although the mean rates are lower (52%) over the 2016/19 three-year period. However, the funnel plots in Figure 8 demonstrate that the regional variability for HLHS is comparatively low with only three regions under 80% for this relatively easily diagnosed condition, as an example of what can be achieved for those with a functionally single ventricle circulation.

Many of the best regions in this three-year period have comparatively low volumes of these 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.

Table 10: *Regional and national variation in antenatal diagnosis rates of infants with hypoplastic left heart syndrome (HLHS), transposition of the great arteries with intact ventricular septum (TGA-IVS), tetralogy of Fallot (Fallot) and complete atrioventricular septal defect (AVSD) who underwent a procedure in the first year of life (2016/17 to 2018/19)*

Nation or English Local Area Team	HLHS	% diagnosed	TGA -IVS	% diagnosed	Complete AVSD	% diagnosed	Fallot	% diagnosed
Channel Islands	0	0	0	0	<3	100.0%	<3	100.0%
England	155	86.6%	124	73.4%	167	54.0%	355	63.6%
Isle of Man	0	0	0	0	<3	100.0%	<3	100.0%
Northern Ireland	16	100%	15	83.3%	9	60.0%	6	42.9%
Republic of Ireland	27	84.4%	13	65%	24	43.6%	28	59.6%
Scotland	5	71.4%	5	71.4%	12	50.0%	25	45.5%
Wales	6	100%	3	100%	4	28.6%	20	76.9%
Local Area Team in England								
Q44. Cheshire, Warrington and Wirral	<3	100%	<3	66.7%	3	42.9%	5	45.5%
Q45. Durham, Darlington and Tees	6	100%	0	0	4	57.1%	4	50.0%
Q46. Greater Manchester	7	87.5%	13	86.7%	11	47.8%	13	68.4%
Q47. Lancashire	3	100%	<3	33.3%	3	42.9%	6	42.9%
Q48. Merseyside	<3	100%	<3	66.7%	<3	40.0%	5	71.4%
Q49. Cumbria, Northumberland, Tyne and Wear	7	87.5%	0	0	8	50.0%	13	65.0%
Q50. North Yorkshire and Humber	6	85.7%	8	88.9%	5	55.6%	5	55.6%
Q51. South Yorkshire and Bassetlaw	6	85.7%	4	57.1%	6	60.0%	16	69.6%
Q52. West Yorkshire	11	91.7%	8	50.0%	9	56.3%	19	57.6%
Q53. Arden, Herefordshire and Worcestershire	6	85.7%	5	83.3%	9	60.0%	3	37.5%
Q54. Birmingham and The Black Country	12	80.0%	5	80.0%	7	46.7%	12	66.7%
Q55. Derbyshire and Nottinghamshire	7	87.5%	8	80.0%	7	58.3%	14	70.0%
Q56. East Anglia	5	100%	4	67.7%	7	46.7%	25	83.3%
Q57. Essex	3	75.0%	4	80.0%	<3	100.0%	14	60.9%
Q58. Hertfordshire and The South Midlands	8	88.9%	8	66.7%	10	52.6%	21	63.6%
Q59. Leicestershire and Lincolnshire	10	100.0%	4	50.0%	6	54.5%	14	77.8%
Q60. Shropshire and Staffordshire	4	100.0%	4	80.0%	<3	28.6%	7	70.0%
Q64. Bath, Gloucestershire, Swindon and Wiltshire	4	100.0%	3	100.0%	5	88.3%	10	66.7%
Q65. Bristol, North Somerset, Somerset and South Gloucestershire	4	100.0%	3	75.0%	3	75.0%	13	86.7%

Nation or English Local Area Team	HLHS	% diagnosed	TGA -IVS	% diagnosed	Complete AVSD	% diagnosed	Fallot	% diagnosed
Q66. Devon, Cornwall & Isles of Scilly	0	0	0	0	<3	50.0%	7	53.8%
Q67. Kent and Medway	5	83.3%	4	100.0%	5	71.4%	16	76.2%
Q68. Surrey and Sussex	7	87.5%	5	83.3%	5	38.5%	10	62.5%
Q69. Thames Valley	5	71.4%	5	83.3%	5	55.6%	13	46.4%
Q70. Wessex	3	100.0%	6	100.0%	10	90.9%	16	69.6%
Q71. London	20	95.2%	21	72.4%	28	60.9%	62	64.65
T03. North Wales	<3	100%	0	0	0	0	3	100.0%
T04. South Wales	5	100%	3	100.0%	4	36.4%	17	73.9%
Local Health Board 7A2	<3	100%	0	0	<3	66.7%	<3	66.7%
Local Health Board 7A3	5	100%	<3	100.0%	0	0	4	66.7%
Local Health Board 7A4	<3	100%	0	0	<3	25.0%	<3	50.0%
Local Health Board 7A5	0	0	0	0	0	0	4	80.0%
Local Health Board 7A6	<3	100%	<3	100.0%	<3	50.0%	6	85.7%
Overseas	<3	22.2%	<3	25.0%	3	23.1%	12	44.4%
Unknown	0	0	0	0	<3	100%	0	0
Total	**209**	**87.1%**	**150**	**73.2%**	**219**	**52.1%**	**62.1%**	**62.1%**

The continued major rises in detection rates in the last few years for transposition of the great arteries and tetralogy of Fallot, 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.

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. As previously, the NCHDA 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).

Recommendation

Hospitals should aim to increase the rate of antenatal diagnosis of conditions requiring intervention in the first year. Individual congenital heart disease networks should take responsibility for improving outcomes and play a pivotal role in reviewing staffing, infrastructure, education and training.

2.3 OUTCOMES: PROCEDURE MORTALITY

Table 11: *Summary of 30-day mortality pertaining to aggregated and specific procedure outcomes (2016/17 to 2018/19)*

QI Metric Description/Name	Centre level risk-adjusted, and procedure-stratified, 30-day mortality following aggregated and specific CHD procedures in children and adults (16 years and over), using three year rolling cohorts of patients.
Why is this important?	Quality assurance following paediatric and congenital cardiac procedures to ensure safe service, and to initiate centre level quality improvement where negative variance detected. Exemplary centre level performance can be used as a benchmark for quality improvement initiatives at less well performing centres.
QI theme (Safety, Effectiveness, Outcomes, Other)	Safety and Outcomes
What is the standard to be met?	1. 30-day mortality at centre and procedure levels for 83 specific CHD procedures looking for negative deviation from averaged national performance. 2. 30-day PRAiS2 risk adjusted mortality at centre level for aggregated surgical procedures in children looking for deviation (positive or negative) from average national performance. 3. 30-day STAT risk adjusted mortality at centre level for aggregated surgical procedures in adults with CHD looking for deviation (positive or negative) from average national performance.
Key references to support the metric	• Improving risk adjustment in the PRAiS model for mortality after paediatric cardiac surgery and improving public understanding of its use in monitoring outcomes http://www.nets.nihr.ac.uk/projects/hsdr/141913 [17] • Fuller SM et al. Estimating Mortality Risk for Adult Congenital Heart Surgery: An Analysis of The Society of Thoracic Surgeons Congenital Heart Surgery Database. Annals Thor Surg 2015; 100 (5), 1728-36.[18]
Method of Calculation	1. Specific procedure algorithm for 83 different surgical, transcatheter and electrophysiological procedures in children and adults with CHD; 2. PRAiS2 risk adjusted model for 30-day outcomes after cardiac surgery in children; 3. STAT risk adjusted model for 30-day outcomes after surgery in adults with CHD
Numerator	Number of patients whose death is recorded by centre or ONS linkage.
Denominator	Total expected risk adjusted mortality
Trends	Overall non-risk adjusted 30-day mortality remains very low by international standards at 1.4%, unchanged from last year.
Variance	No negative centre level outliers detected for 30-day mortality outcomes following any of the 83 specific procedures, or aggregated surgery in children or adults with CHD

Hospitals providing care for children and adults with CHD 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 9]. For the 2019 NCHDA report, a new bespoke risk model was used, based on the adult congenital heart surgery mortality score derived from Society of Thoracic Surgeons–European Association for Cardio-thoracic Surgery (STAT) mortality score used in North America and Europe[18] to assess outcomes in adults (over 16 years of age) born with CHD, and this model was again used in this years' report.

NCHDA focuses on improving the quality and safety of congenital cardiac procedures in children and adults. The ability to collect, analyse and report on procedural outcome data is a marker of quality assurance and safety assurance with possible in-house quality improvement measures undertaken following monthly within centre review of VLAD charts. 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.

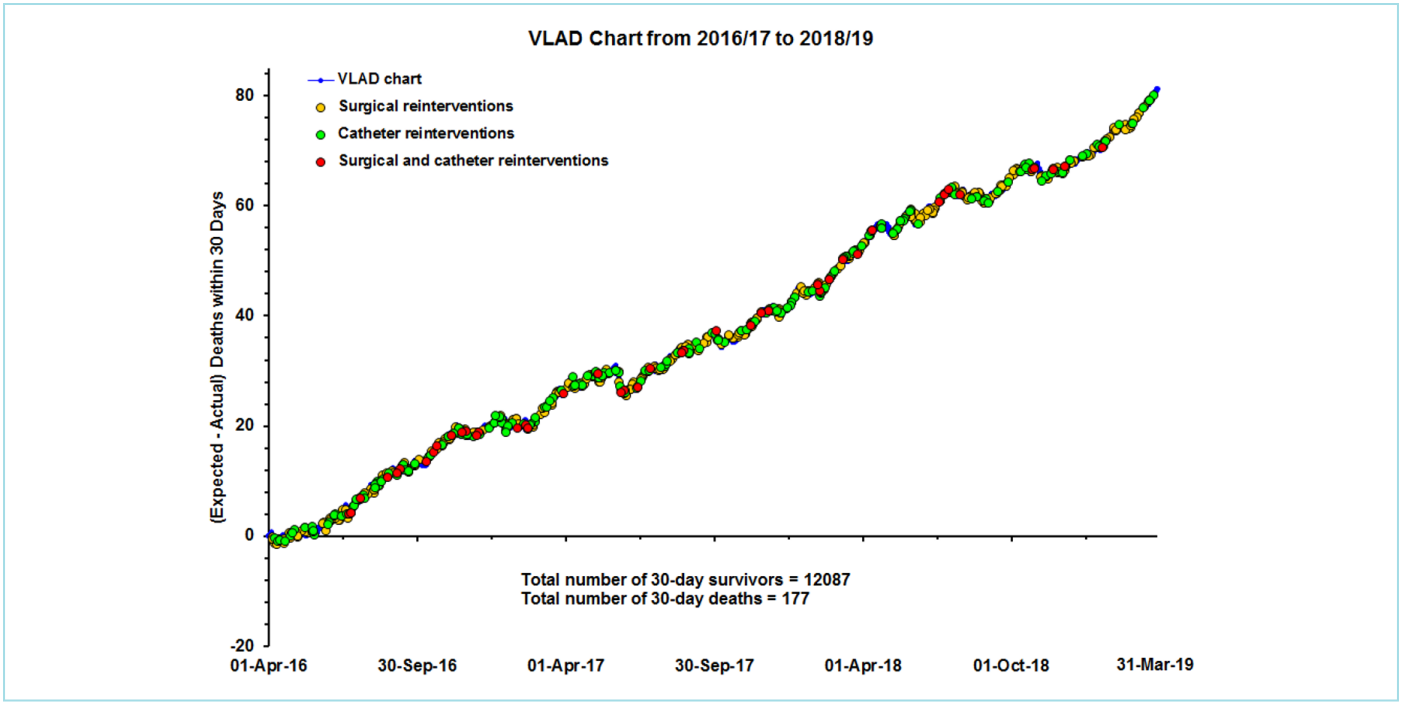
However, there is increasing focus on outcome measures rather than mortality only. Outcome measures assess the effect of care on the health of patients, such as 30-day mortality and morbidity rates, length of stay, readmission rates, patient satisfaction, health-related quality of life, cost-effectiveness, and resource use.

2.3.1 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. 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. [17]

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 continue to have excellent outcomes with very low mortality rates.

Figure 9: *Variable Life Adjusted Display (VLAD) Chart for all 12 paediatric centres in the UK and Republic of Ireland undertaking procedures in patients under 16 years of age (2016/17 to 2018/19)*



The VLAD chart depicted in Figure 9 shows the national outcomes between 1 April 2016/17 and 31 March 2018/19, with surgical procedures represented by the orange 'VLAD chart' line, somewhat hidden by the re-intervention dots. The VLAD chart line has consistently continued to rise 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, 259 deaths were predicted compared to 177 actual deaths, a difference of 82 or 32% 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 9 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 12,087 shown here) and therefore the individual dots are easier to discriminate visually from the underlying blue alive-status line.

These displays, therefore, enable clinical teams to identify and review clusters of re-interventions following a review of VLAD charts within regular governance or morbidity conferences (usually monthly). Some of these will be planned re-interventions, but the focus by the centres will be on any unplanned additional procedures that are highlighted by the VLAD chart, and any 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 remain unchanged to approximately 1.4% of 4326 surgical operations undertaken in children under 16 years of age [Figure 10] in 2018/19.

Although the VLAD trend and these crude mortality rates remain very good, 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. It is also an indication that the PRAiS2 model should be recalibrated again to reflect outcomes over the last few years and this is planned for mid-2021. Nevertheless, 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).[19, 22]

Figure 10: *Trends in 30 days unadjusted mortality after surgery over 11 years (financial years 2008/09 to 2018/19) in children (under 16 years)*

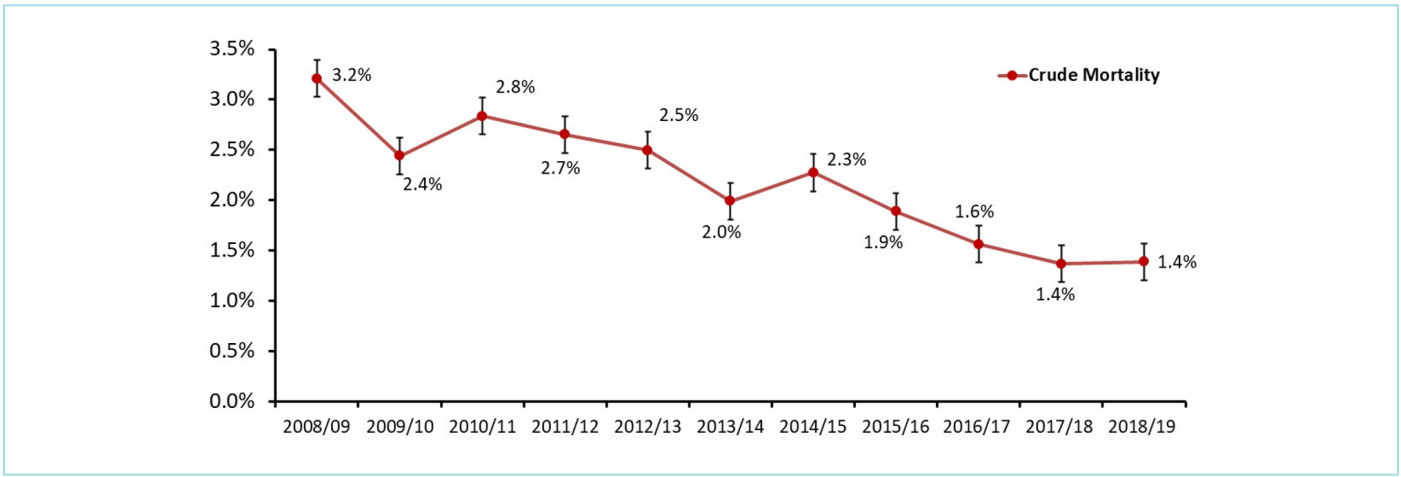
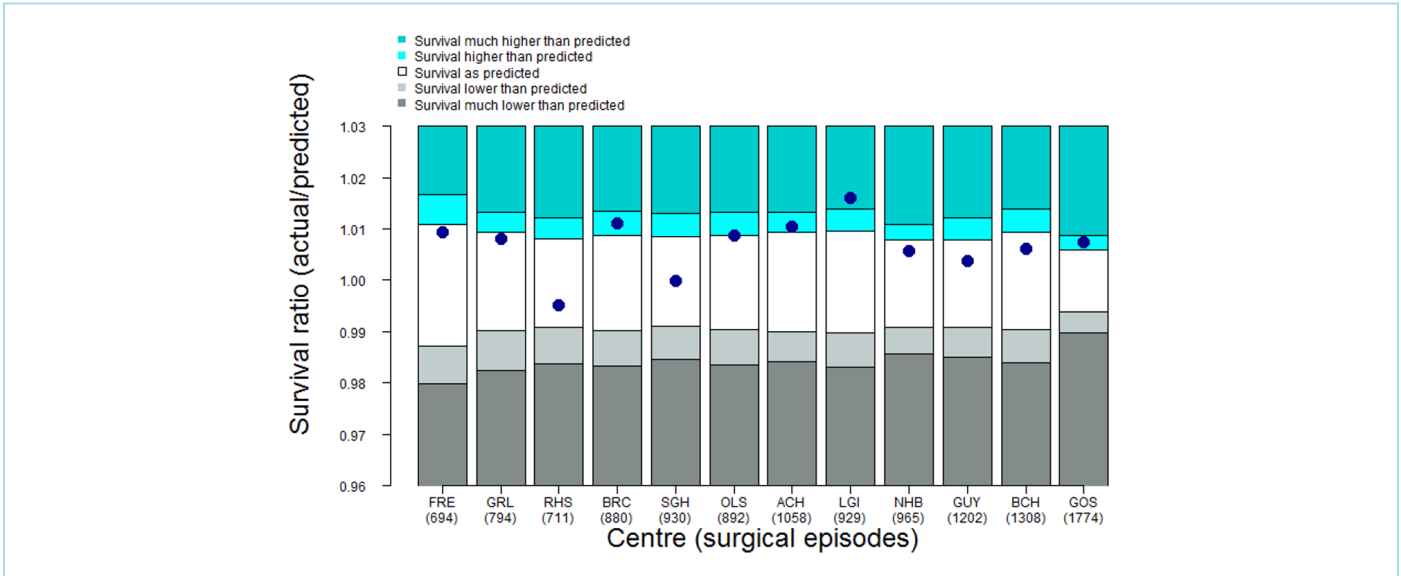


Figure 11: *Actual vs Predicted Survival for all 12 centres in the UK and Republic of Ireland undertaking cardiac procedures in patients under 16 years of age 2016/17 to 2018/19 using PRAiS2 risk adjustment methodology*



Abbreviations: 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 11 bar chart shows whether each centre's actual survival is significantly different from the predicted survival derived from the PRAiS2 model where the upper two zones (i.e. bright azure and azure) show higher and much higher than predicted survival and lower two zones (i.e. bright cyan and cyan) show lower and much lower than predicted survival. 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 12: *Actual and Predicted Survival in 2016/17 to 2018/19, using PRAiS2 Risk Adjustment methodology with average predicted risk per case, for all 12 units undertaking procedures in patients under 16 years of age*

Hospital	Centre Code	Surgical Episodes	Survivors	Deaths	Predicted Survival	Actual/ Predicted	Survival summary	Average Predicted Mortality Per Case
Newcastle Freeman Hospital	FRE	694	683	11	97.5%	1.009	as predicted	2.50%
Leicester Glenfield Hospital	GRL	794	785	9	98.1%	1.008	as predicted	1.93%
Glasgow Royal Hospital for Children	RHS	711	697	14	98.5%	0.995	as predicted	1.49%
Bristol Royal Hospital for Children	BRC	880	871	9	97.9%	1.011	higher than predicted	2.11%
Southampton Wessex Cardiothoracic Centre	SGH	930	912	18	98.1%	1.000	as predicted	1.92%
Dublin Our Lady's Children's Hospital	OLS	892	881	11	97.9%	1.009	as predicted	2.09%
Liverpool Alder Hey Hospital	ACH	1058	1043	15	97.6%	1.010	higher than predicted	2.43%
Leeds General Infirmary	LGI	929	923	6	97.8%	1.016	much higher than predicted	2.22%
London Royal Brompton Hospital	NHB	965	954	11	98.3%	1.006	as predicted	1.70%
London Evelina London Children's Hospital	GUY	1202	1179	23	97.7%	1.004	as predicted	2.27%
Birmingham Children's Hospital	BCH	1308	1276	32	97.0%	1.006	as predicted	3.04%
London Great Ormond Street Hospital for Children	GOS	1774	1759	15	98.4%	1.008	higher than predicted	1.59%

The results in Figure 11 and Table 12 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.

Three centres performed 'better' than predicted (Alder Hey Children's Hospital, Liverpool (fifth year running); Bristol Royal Hospital for Children (second year running); and Great Ormond Street Hospital, London (following 4 years of performing 'much better' than predicted)), whilst this year one centre, Leeds General Infirmary, Leeds, was 'much better' than predicted. This is indicative of good performance and represents an opportunity for sharing more optimal practice across specialist centres.

The Congenital Audit also calculates the average PRAiS2 risk adjusted mortality per patient operated upon at each of the 12 centres, as a way to understand the relative complexity of cases at each centre [Table 12, last column]. This shows significant variance between centres (Chi-Squared test, P value < 0.001), from 1.49% to 3.04%, suggesting, for instance, that the two largest centres (Birmingham

Children's Hospital and Great Ormond Street Hospital for Children) operate upon groups of patients with significantly different risk profiles. Some centres, for instance, such as Glasgow, are known to send many of their most complex patients to England for Norwood procedures. Having said this, the PRAiS2 model should largely take these differences into account. Future work for the Congenital Audit will include understanding case-mix proportions by centre and which procedures account for most of this variation.

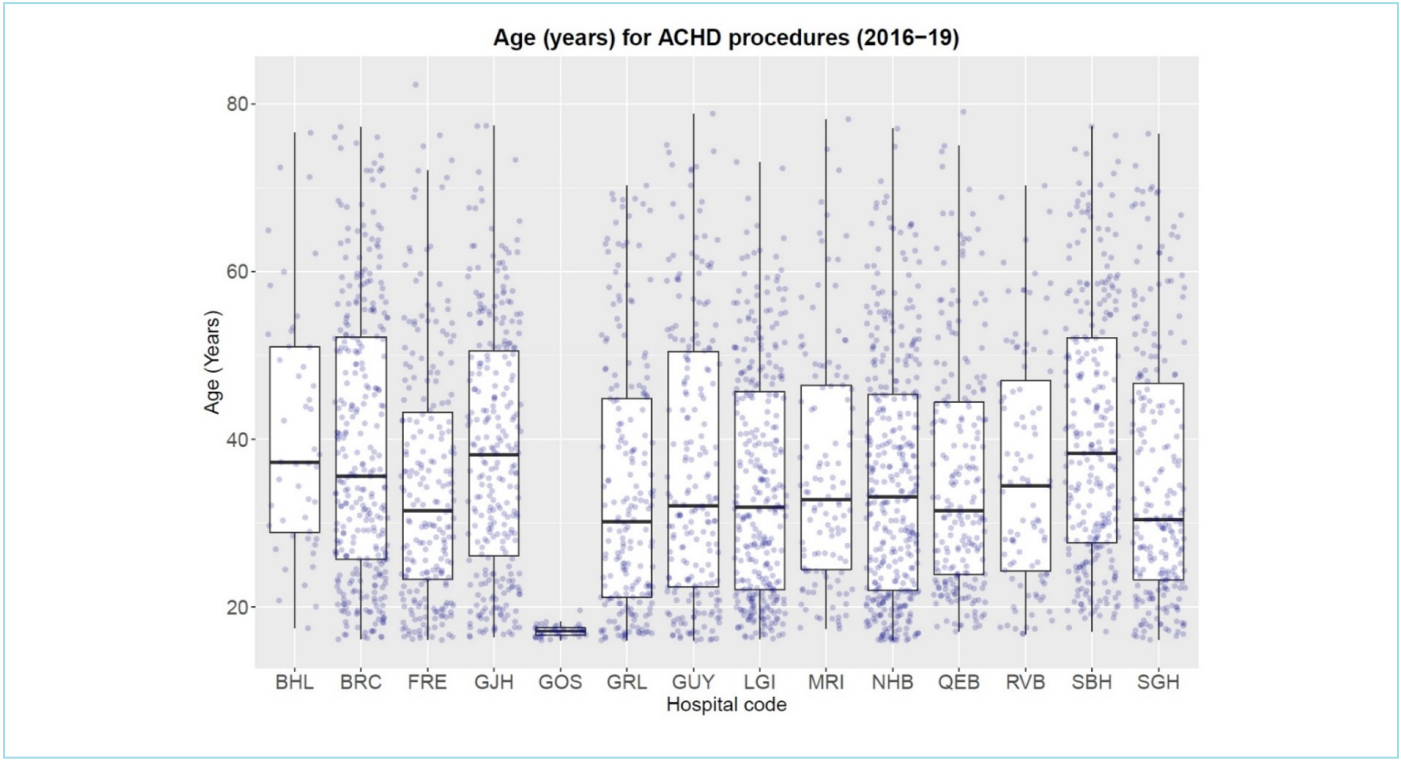
2.3.2 30-DAY SURVIVAL AFTER 83 SPECIFIC PROCEDURES

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 has been a two-step increase from the 57 procedures reported in 2011/12 to 2013/14, to 72 procedures subsequently and the current 83 specific procedures reported since 2017/18. 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 and outcomes of activity for the different procedure categories and specific procedures for each congenital heart centre, click here. Funnel plots for each specific procedure are also available here. NICOR follows the Department of Health Outlier Policy[20] which sets out a process for providing assurance that all hospitals provide the expected quality of care. For details click here.

2.3.3 30-DAY AGGREGATE SURVIVAL AFTER CONGENITAL HEART SURGERY IN ADULTS

Adults who undergo surgery for congenital cardiac malformations represent just under 20% of CHD surgical activity across the UK. This year the Congenital Audit examined the age range of those undergoing these operations at those centres undertaking over 30 procedures during 2016/19. The results are shown in Figure 13 and illustrate that the bulk of work undertaken by centres is for individuals between 20 and 50 years of age but there is a huge range from 16 years to over 80 years of age. The exception is Great Ormond Street Hospital for Children, who, as the name suggests, do not take on operations in adults over 18 years of age. However, it is also important to understand that aortic valve surgery in older adults with CHD is often undertaken by surgeons who otherwise only operate on adults with acquired heart disease. Adult acquired surgical data and outcomes are submitted to the National Adult Cardiac Surgery Audit (NACSA), a separate Domain within NICOR. The Congenital Audit has arbitrarily set an upper age of 40 years for submission of data on individuals having aortic valve procedures, whilst data on older patients is submitted to the NACSA.

Figure 12: *Age distribution of adults undergoing surgery for CHD at the 14 centres undertaking over 30 procedures (2016/17 to 2018/19)*



The box in each column for each centre represents the median of patient ages (middle bold line) and quartiles (1st and 3rd) instead of mean and standard deviations. The box plots illustrate and compare the age distribution (skewness) of patients 16 years of age and older who have undergone CHD procedures.

The Congenital Audit has 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,[18] 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 postoperative outcomes of 12,513 adults with congenital heart disease (over 17 years of age, in hospital deaths) from 116 North American centres 2000/01 to 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 on which 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. Due to resource issues and the pandemic, the planned more detailed mapping exercise with a group of clinicians to establish 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, was not possible for this report. This is still planned for next year's report.

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.

Figure 13 bar chart graphically illustrates whether each centre's actual survival is significantly different from the predicted survival derived from the estimated mortality according to the STAT procedure category where the upper two zones (i.e. bright azure and azure) show higher and much higher than predicted survival and the lower two zones (i.e. bright cyan and cyan) show lower and much lower than predicted survival for their own. 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 (99.9% 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. 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 13].

Figure 13: *Actual vs Predicted Survival for the 14 centres in the UK undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over in 2016/17 to 2018/19 using STAT mortality score methodology*

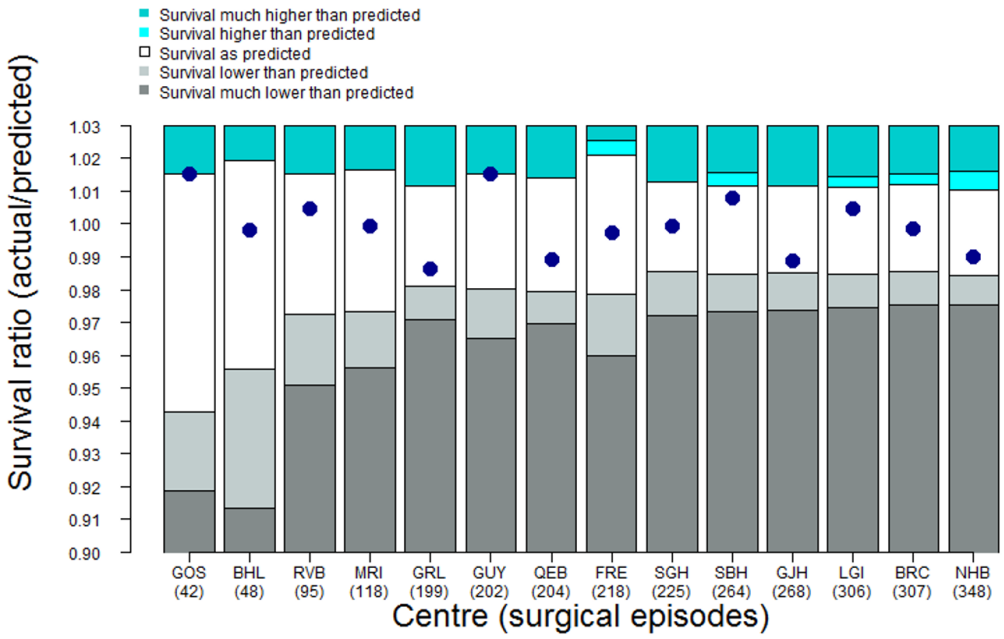


Table 13: *Actual and Predicted Survival in 2016/17 to 2018/19, using STAT mortality risk methodology to give the average predicted risk of death per case for the 14 centres undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over*

Hospital	Centre Code	Surgical Episodes	Survivors	Deaths	Actual Survival	Predicted Survival	Actual vs Predicted Survival	Average Predicted Mortality Per Case
London Great Ormond Street Hospital for Children	GOS	42	42	0	100.00%	98.48%	1.015	1.52
Liverpool Heart and Chest Hospital	BHL	48	4*	<3	>93.7%	98.09%	>0.96	1.91
Belfast Royal Victoria Hospital	RVB	95	9*	<3	>96.8%	98.51%	>0.98	1.49
Manchester Royal Infirmary	MRI	118	11*	<3	>97.5%	98.37%	>0.99	1.63
Leicester Glenfield Hospital	GRL	199	194	5	97.49%	98.86%	0.986	1.14
London Evelina London Children's Hospital	GUY	202	202	0	100.00%	98.50%	1.015	1.50
Birmingham Queen Elizabeth Hospital	QEB	204	199	5	97.55%	98.60%	0.989	1.40
Newcastle Freeman Hospital	FRE	218	212	6	97.25%	97.51%	0.997	2.49
Southampton Wessex Cardiothoracic Centre	SGH	225	222	3	98.67%	98.75%	0.999	1.25
London Barts Heart Centre	SBH	264	26*	<3	>98.9%	98.47%	>1.0	1.53
Glasgow Golden Jubilee National Hospital	GJH	268	262	6	97.76%	98.87%	0.989	1.13
Leeds General Infirmary	LGI	306	303	3	99.02%	98.58%	1.004	1.42
Bristol Royal Hospital For Children	BRC	307	302	5	98.37%	98.51%	0.999	1.49
London Royal Brompton Hospital	NHB	348	339	9	97.41%	98.40%	0.990	1.60
Other centres (12)	-	154	15*	<3	>98%	98.59%	>0.99	1.41
Overall		2,998	2,948	50	98.33%	98.50%	0.998	1.50

The outcome results in Table 13 and Figure 13 show that there were 2,998 adult patients operated upon during 2016/19. The overall actual to predicted mortality ratio was 0.998, and this year there were approximately 10% more deaths than predicted by the STAT mortality model: predicted deaths were 45, whilst actual deaths were 50. In the 2015/18 three-year analysis, there were 19% fewer deaths than predicted, indicating that overall, 30-day mortality in these patients was higher in 2018/19. The reasons for this are unclear as there were no centre level outliers for aggregated outcomes as shown in Figure 13. All 14 centres that undertook more than 30 operative procedures in 2016/17 to 2018/19 performed such that 30-day survival was as predicted, given the alert and alarm control limits, after all surgical procedures in adults with congenital heart disease. In addition, there were no centre level outliers for any of the 44 specific surgical procedures analysed for 30-day mortality. This suggests that the outcomes are likely not to be outside the statistically acceptable limits used within the STAT risk-adjustment model.

COMMENTARY

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 second year analyses using the new complication linked fields are reported below.

Unfortunately, the planned investigation of the validity of reporting post-procedural 60 and 90-day mortality outcomes in general and after certain specific procedures was not possible this year due to insufficient time and analytical resources following the ongoing COVID-19 pandemic. The same issues also meant that the planned analyses focussing on the incidence of unplanned additional therapeutic procedures following surgery and transcatheter interventions could also not be undertaken in time for the current report. We are committed however to completing the validation steps necessary to include these new metrics.

2.4 OUTCOMES: POST-PROCEDURAL COMPLICATIONS IN CHILDREN

Table 14: *Summary of post-procedural complications*

QI Metric Description/Name	**Incidence of seven post-procedure complications:** **- Adverse neurological outcome** **- Use of extracorporeal life support** **- Need for renal replacement therapy** **- Unplanned need for a pacemaker** **- Prolonged pleural drainage** **- Need for emergency procedure following catheter intervention** **- Embolisation of transcatheter implanted device**
Why is this important?	Quality assurance with possible quality improvement recommendation(s) following investigation with aim to reduce inter-centre variance by drilling down at centre level (by age and specific procedure), to establish best practice to minimise the incidence of each complication by future benchmarking at CHD procedural level.
QI theme	Safety and Outcomes
What is the standard to be met?	No standards, but least incidence is optimal
Key references	• Brown KL et al. Incidence and risk factors for important early morbidities associated with paediatric cardiac surgery in a UK population. J Thorac Cardiovasc Surg 2019: 158(4):1185-96[21] • Jacobs JP. Introduction – Databases and the assessment of complications associated with the treatment of patients with congenital cardiac disease. Cardiol Young 2008; 18(Suppl. 2): 1–37[22] • Brown KL, Pagel P, Brimmell R, Bull K, Davis P, Franklin RC et al. Definition of important early morbidities related to paediatric cardiac surgery. Card Young 2017; 27: 747–756[23]
Method of Calculation	1. Specific procedure algorithm for 83 different surgical, transcatheter and electrophysiological procedures in children and adults with CHD; 2. PRAiS2 risk adjusted model for 30-day outcomes after cardiac surgery in children; 3. STAT risk adjusted model for 30-day outcomes after surgery in adults with CHD
Numerator	Count of patients with a coded complication
Denominator	Countable surgical procedures
Trends	N/A 5 years aggregate for individual hospitals planned in the future when enough data are accumulated.
Variance	Some inter-centre variance seen in the incidence of each complication. Detailed case-mix and specific procedure adjusted analysis of causation required in the future to establish best practice for benchmarking.

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 to 2017/18. Clinicians involved included members of the NCHDA Domain Expert Group. Within this study, families and clinicians prioritised the following as principle postoperative 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 infection, and prolonged pleural effusion or chylothorax.[23] 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 and 6 months survival was less when morbidities were documented (88·2% compared to 99·3%) without a morbidity.[21]

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 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. In fact, the WHO has decided to call these post-procedural disorders, in an attempt to address this within the eleventh iteration of the International Classification of Disease (ICD-11). A procedure related complication is any complication (disorder), 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.[22] For full definitions of complications analysed in this cycle, see Appendix 3.

30-day procedure related complication rates for children (less than 16 years of age) following 12,821 surgical procedures and 9,357 transcatheter interventions at 12 UK and Republic of Ireland centres during 2016/19 are reported. There are two important reasons why the data should be interpreted with caution and regarded as somewhat preliminary again 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 [Figure 3]. The second is the variable data quality for complications data, which was especially variable for adult patients and so this analysis was again not undertaken. Further, one private paediatric centre, the Harley Street Clinic, was also excluded due to non-submission of data in 2017/18 and poor data quality in this area for previous years (no complications reported). All other centres submitted complication data and an assumption was again made that when the complication fields were blank, that no complication occurred (a small minority of cases at nearly all centres).

The analyses focussed on 5 surgical and 2 interventional catheter related complications.

2.4.1 ACUTE SURGERY RELATED NEUROLOGICAL EVENT

Overall, there were 147 patients affected with a low overall rate of 1.2% (range per centre 0.3-2.6%): neonatal 2.1% (50/2,309), infant 1.0% (54/5,265), child 0.8% (43/5,154). Results per centre are shown in Table 15, 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 repair of: congenitally corrected transposition of the great arteries (double switch, or switch-Rastelli procedures) at 7.7% (2/26), complex transposition of the great arteries with or without arch repair at 6.5% (3/46), Norwood procedure (e.g. for hypoplastic left heart syndrome) at 5.3% (15/284), and 4.6% for Ross-Konno procedure (e.g. for mixed aortic valve disease and left ventricular outflow obstruction) (3/66) and repair of common arterial trunk (3/66) at 4.6% (3/66). 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 currently covered by this audit. This means that these procedural disorders are relatively subjective and non-binary in contrast to the need, for instance, to have postprocedural renal support therapy using dialysis.

Table 15: *Incidence of surgery related acute neurological event in children (under 16 years of age) at the 12 UK and Republic of Ireland centres (2018/19)*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1,356	24	1,380	1.74%
Bristol Royal Hospital for Children	BRC	943	3	946	0.32%
Dublin - Our Lady's Children's Hospital	OLS	942	6	948	0.63%
Glasgow - Royal Hospital for Sick Children	RHS	749	20	769	2.60%
Leeds General Infirmary	LGI	955	3	958	0.31%
Leicester - Glenfield Hospital	GRL	841	4	845	0.47%
Liverpool - Alder Hey Hospital	ACH	1,117	8	1,125	0.71%
London - Evelina Children's Hospital	GUY	1,216	30	1,246	2.41%
London - Great Ormond Street Hospital for children	GOS	1,864	29	1,893	1.53%
London - Royal Brompton Hospital	NHB	984	12	996	1.20%
Newcastle - Freeman Hospital	FRE	743	<3	74*	0.13%
Southampton University Hospital	SGH	964	7	971	0.72%
Total		**12,674**	**14***	**12,8****	**1.15%**

2.4.2 POST-SURGICAL USE OF EXTRACORPOREAL LIFE SUPPORT (ECMO) (2018/19)

The overall rate of this important and impactful adverse event was 2.3% (range per centre 0.7-5.1%): neonatal 5.3% (125/2,359), infant 2.0% (104/5,265), child 1.3% (65/5,197). There is similar centre-related variability to the 2015-18 analyses with highest rates in Glasgow (5.1%) and those with a national ECMO program (Newcastle, Leicester; 3.1-3.8%), as shown in Table 16. 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, [24] and in the NCHDA data. Highest postoperative ECMO rates were following repair of common arterial trunk with aortic arch obstruction at 31.3% (5/66) or without at 12.1% (8/66), heart transplantation at 16.8% (19/105), a Norwood procedure at 14.7% (41/279), and repair of anomalous coronary artery at 11.8% (8/68).

Table 16: *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 (2018/19)*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1,355	25	1,380	1.81%
Bristol Royal Hospital for Children	BRC	932	14	946	1.48%
Dublin - Our Lady's Children's Hospital	OLS	931	17	948	1.79%
Glasgow - Royal Hospital for Sick Children	RHS	730	39	769	5.07%
Leeds General Infirmary	LGI	945	13	958	1.36%
Leicester - Glenfield Hospital	GRL	813	32	845	3.79%
Liverpool - Alder Hey Hospital	ACH	1,090	35	1,125	3.11%
London - Evelina Children's Hospital	GUY	1,226	20	1,246	1.61%
London - Great Ormond Street Hospital for children	GOS	1,849	44	1,893	2.32%
London - Royal Brompton Hospital	NHB	971	25	996	2.51%
Newcastle - Freeman Hospital	FRE	721	23	744	3.09%
Southampton University Hospital	SGH	964	7	971	0.72%
Total		**12,527**	**294**	**12,821**	**2.29%**

2.4.3 INCIDENCE OF POST-SURGICAL RENAL REPLACEMENT THERAPY (DIALYSIS)

The overall rate was 3.5% (range per centre 1.0-6.9%): neonatal 9.7% (228/2,359), infant 2.4% (125/5,265), child 1.8% (92/5,197). Similar to last year there is considerable inter-centre variability from under 1.5% (Dublin, Leicester, Birmingham) to 5-7% (Liverpool, Glasgow, Bristol), as shown in Table 17. 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 repair of common arterial trunk with 25% (4/16) or without arch obstruction at 18.2% (12/66), repair of complex transposition with arch obstruction 23.9% (11/46) or without arch obstruction (7/48) in 20% of cases having a Norwood procedure (56/279) or lung transplant (5/24) and repair of total anomalous pulmonary venous connection at 14.3% (24/168).

Table 17: *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 (2018/19)*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1,363	17	1,380	1.23%
Bristol Royal Hospital for Children	BRC	881	65	946	6.87%
Dublin - Our Lady's Children's Hospital	OLS	939	9	948	0.95%
Glasgow - Royal Hospital for Sick Children	RHS	727	42	769	5.46%
Leeds General Infirmary	LGI	936	22	958	2.30%

Hospital	Centre Code	No	Yes	Total	%
Leicester - Glenfield Hospital	GRL	833	12	845	1.42%
Liverpool - Alder Hey Hospital	ACH	1,060	65	1,125	5.78%
London - Evelina Children's Hospital	GUY	1,194	52	1,246	4.17%
London - Great Ormond Street Hospital for Children	GOS	1,815	78	1,893	4.12%
London - Royal Brompton Hospital	NHB	961	35	996	3.51%
Newcastle - Freeman Hospital	FRE	720	24	744	3.23%
Southampton University Hospital	SGH	947	24	971	2.47%
Total		**12,376**	**445**	**12,821**	**3.47%**

2.4.4 POST-SURGICAL REQUIREMENT FOR A PACEMAKER (UNPLANNED)

Overall, there were 143 cases with, again, this year a somewhat reassuringly low rate of 1.1% (range per centre 0.5-2.9%): neonatal 0.3% (7/2,359), infant 1.0% (54/5,265), child 1.6% (82/5,197). There was some inter-centre variability [Table 18], 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: repair of congenitally corrected transposition of the great arteries (double switch, or switch-Rastelli procedures) at 31% (8/26), and tricuspid (9.1%, 1/11) or mitral valve replacement (6.6%, 8/121).

Table 18:*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 (2018/19)*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1,364	16	1,380	1.16%
Bristol Royal Hospital for Children	BRC	919	27	946	2.85%
Dublin - Our Lady's Children's Hospital	OLS	940	8	948	0.84%
Glasgow - Royal Hospital for Sick Children	RHS	753	16	769	2.08%
Leeds General Infirmary	LGI	953	5	958	0.52%
Leicester - Glenfield Hospital	GRL	840	5	845	0.59%
Liverpool - Alder Hey Hospital	ACH	1,112	13	1,125	1.16%
London - Evelina Children's Hospital	GUY	1,241	5	1,246	0.40%
London - Great Ormond Street Hospital for Children	GOS	1,878	15	1,893	0.79%
London - Royal Brompton Hospital	NHB	985	11	996	1.10%
Newcastle - Freeman Hospital	FRE	737	7	744	0.94%
Southampton University Hospital	SGH	956	15	971	1.54%
Total		**12,678**	**143**	**12,821**	**1.12%**

2.4.5 POST-SURGICAL REQUIREMENT FOR PROLONGED PLEURAL DRAINAGE (GREATER THAN 7-10 DAYS)

Overall, there were 608 cases with a rate of 4.7% (range per centre 0.4-13.6): neonatal 4.8% (113/2,359), infant 3.5% (182/5,265), child 6.0% (313/5,197). There were again clear differences between centres with highest rates at Glasgow (13.6%) and Birmingham (10.4%), as shown in Table 19, 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 (38%; 197/519) and lung transplant (33.3%; 8/24), as well as about 25% of those undergoing a Rastelli procedure (10/41) or repair of atrioventricular septal defect with tetralogy of Fallot (8/31). As of last year, the Congenital Audit has changed 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 19: *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 (2018/19)*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1,236	144	1,380	10.43%
Bristol Royal Hospital for Children	BRC	905	41	946	4.33%
Dublin - Our Lady's Children's Hospital	OLS	898	50	948	5.27%
Glasgow - Royal Hospital for Sick Children	RHS	664	105	769	13.65%
Leeds General Infirmary	LGI	954	4	958	0.42%
Leicester - Glenfield Hospital	GRL	842	3	845	0.36%
Liverpool - Alder Hey Hospital	ACH	1,084	41	1,125	3.64%
London - Evelina Children's Hospital	GUY	1,216	30	1,246	2.41%
London - Great Ormond Street Hospital for Children	GOS	1,801	92	1,893	4.86%
London - Royal Brompton Hospital	NHB	962	34	996	3.41%
Newcastle - Freeman Hospital	FRE	735	9	744	1.21%
Southampton University Hospital	SGH	916	55	971	5.66%
Total		**12,213**	**608**	**12,821**	**4.74%**

2.4.6 CATHETER PROCEDURE REQUIREMENT FOR EMERGENCY COMPLICATION-RELATED PROCEDURE (SURGERY OR TRANSCATHETER)

Overall, there were 70 cases with, again, a reassuringly low rate of 0.8% (range per centre 0.3-1.5; Table 20): neonatal 2.7% (25/940), infant 1.1% (20/1,809), child 0.4% (25/6,608) [Table 20]. Most frequent procedures were not surprisingly neonatal radiofrequency pulmonary valve perforation-dilation (2 of 36 cases, 5.7%) and stent placement in the right ventricular outflow tract (6 of 208 cases, 2.3%), as both procedures may involve inadvertent perforation of the right ventricular or pulmonary outflow tracts. Stent placement to maintain arterial duct patency was also relatively high at 6.0% (11/185).

Table 20: *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 (2018/19)*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1,005	9	1,014	0.89%
Bristol Royal Hospital for Children	BRC	763	5	768	0.65%
Dublin - Our Lady's Children's Hospital	OLS	1,275	8	1,283	0.62%
Glasgow - Royal Hospital for Sick Children	RHS	491	3	494	0.61%
Leeds General Infirmary	LGI	844	4	848	0.47%
Leicester - Glenfield Hospital	GRL	379	<3	38*	>0.25%
Liverpool - Alder Hey Hospital	ACH	796	8	804	1.00%
London - Evelina Children's Hospital	GUY	605	9	614	1.47%
London - Great Ormond Street Hospital for Children	GOS	906	5	911	0.55%
London - Royal Brompton Hospital	NHB	1,114	11	1,125	0.98%
Newcastle - Freeman Hospital	FRE	489	<3	49*	>0.40%
Southampton University Hospital	SGH	620	5	625	0.80%
Total		**9,287**	**70**	**9,357**	**0.75%**

2.4.7 CATHETER-RELATED DEVICE EMBOLISATION

Overall, there were 62 cases with, again, a reassuringly low rate of 0.7% (range per centre 0.1-1.6): neonatal 0.7% (7/940), infant 1.1% (19/1,809), child 0.5% (36/6,608). There was some inter-centre variability likely reflecting case complexity [Table 21], but also possibly the increasing use of the transcatheter route for closing a patent arterial duct in prematurely born neonates and infants (1.9%; 33/1678).

Table 21: *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 (2018/19)*

Hospital	Centre Code	No	Yes	Total	%
Birmingham Children's Hospital	BCH	1,007	7	1,014	0.69%
Bristol Royal Hospital for Children	BRC	766	<3	76*	>0.25%
Dublin - Our Lady's Children's Hospital	OLS	1,277	6	1,283	0.47%
Glasgow - Royal Hospital for Sick Children	RHS	489	5	494	1.01%
Leeds General Infirmary	LGI	842	6	848	0.71%
Leicester - Glenfield Hospital	GRL	379	<3	38*	>0.25%
Liverpool - Alder Hey Hospital	ACH	798	6	804	0.75%
London - Evelina Children's Hospital	GUY	610	4	614	0.65%
London - Great Ormond Street Hospital for Children	GOS	910	<3	91*	>0.10%
London - Royal Brompton Hospital	NHB	1,107	18	1,125	1.60%
Newcastle - Freeman Hospital	FRE	488	3	491	0.61%
Southampton University Hospital	SGH	622	3	625	0.48%
Total		**9,295**	**62**	**9,357**	**0.66%**

3. 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:

DATA QUALITY AND NATIONAL QUALITY IMPROVEMENT (QI) METRIC TOOL

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 NCHDA 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 number and reporting of deaths to NHS Digital, the Congenital Audit's validation protocols have internationally been recognised as exemplary.[1]

In an effort to further advance quality improvement and quality assurance, NICOR along with the Professional Societies have developed a new IT feature, the national quality improvement metric tool. This tool will help audit teams and hospitals drive up data quality and completeness to improve efficiency and accuracy of data reported and how these translate to improved clinical practice and patient outcomes.

The QI tool will allow hospitals to compare themselves on a continuous basis for each QI metric with the national average as well as the best centres. The tool also allows for more autonomous management of the accuracy and completeness of hospital data. If hospital data do not appear to be correct, there will be time to check data and make appropriate valid corrections to improve its accuracy in a timely way. The tool also provides an overview of data completeness for each QI metric, which will be linked to validation rules embedded in both the dataset and database live on the QReg5 platform. This will enable you to drill down to individual patient records and identify where data are missing or incorrect. The QI metric tool for the NCHDA will be rolled out in 2021.

FLUOROSCOPY

Children and young adults are more radiosensitive to ionising radiation than the population as a whole and their longer lifespan provides more opportunity for long-term effects of ionising radiation to emerge. Ionising radiation is an important and necessary part of the care of children and adults with congenital heart disease, who may be have an increased longer-term risk of cancer, therefore less is better. The Ionising Radiation Medical Exposure Regulations (IR(ME)R, 2017) and the Care Quality Commission (CQC) inspection programme of specialist paediatric radiology services (2019) requires hospitals to pay particular attention to medical exposure to radiation in children. It is therefore important to understand the variance between Trusts for the same congenital heart procedure at different ages.

There are no published diagnostic reference levels (DRLs) for congenital catheter procedures in children or adults or established national standards that would allow centres to reference against. In response, this year the NCHDA sought to begin the process of helping centres fulfil these requirements and publish DRLs in a preliminary form. Centres performing more than 500 catheter procedures per year were included in the preliminary analysis. Five procedures were chosen (i.e. Relationship of patient age, patient weight to exposure dose and fluoroscopy time) to provide centres with an opportunity to bench-mark against. The procedures were chosen where more than 500 procedures were performed per year nationally. We are in the early stages of refining our criteria to support more accurate data collection, which we aim to add to our existing QI metrics. We hope that we will be able to provide referencing standards for commonly performed procedures that centres can use for dose reduction initiatives where possible, including in-house comparison of variance between individual operators. Initial findings of these data will be published in 2021.

UNPLANNED REOPERATIONS

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 NCHDA 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.[2]

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. The data were examined for the first time using submitted 2015/18 data and unfortunately revealed significant data quality issues, which require further refinement of criteria and guidance, which was undertaken last year. Centres made a concerted effort to improve submitted data quality following a validation exercise begun in November 2019. We had hoped to report on these results in the current report. However, due to lack of analytical resources within NICOR, compounded by the COVID-19 pandemic, this has not proved possible.

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 that NCHDA will shortly move to (QReg5), before finally going live later this year.

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 in 2017 to enable bidirectional data-sharing between NCHDA and NCARDRS to optimise data quality and full case ascertainment.

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APPENDIX 1: DATA QUALITY INDICATOR (DQI)

The DQI is an assessment of quality of the data across 4 domains. These are demographics, such as name, NHS Number, post code and date of birth; pre-procedure metrics include weight, diagnosis, previous procedures and comorbidities, procedure metrics include procedure performed, devices implanted, perfusion times, X-ray time and dose and outcome metrics include complications, post procedure seizures length of ventilation and date of discharge. Each domain has a total possible score of variables. Twenty patients' case notes are examined across these domains and each are scored on their completeness and accuracy. Note that 20 patients may have over 30 procedures in the data period being reviewed.

Once each domain is scored, this enables hospitals to see where there may be a difficulty or challenge if an actual domain score is below what is expected i.e. the total number of variables. The mean of the total sum of the domain score is used in the table below to describe the overall DQI.

Data Quality Indicator score gives an indication of the quality of the data submitted by each centre against expected NCHDA Standard.

DATA QUALITY SCORES

The overall score for a hospital is calculated as an average of the total score of the 4 domains. Due to the nature and wide range of the numbers of variables, this is a manual calculation. Table 22 shows the coloured DQI displaying overall DQI for centres and is RAG rated. It can be clearly seen using the RAG system that centres who score more than 98% overall are of an extremely high standard, green is good, amber is acceptable and red is a cause for concern.

Table 22: *Overall DQI for all centres submitted to NCHDA for 5 years (2014/15 to 2018/19)*

Paediatric/Mixed Practice Hospitals	Code	2014/15	2015/16	2016/17	2017/18	2018/19	No of actual WTE DBM's for (2018/19)	No of WTE recommended in the NHSE Standards 2016
Belfast, Royal Victoria Hospital	RVB	98.75	98.25	94.50	*	*	see below	see below
Birmingham Children's Hospital	BCH	98.50	97.75	99.50	99.00	99.00	2.00	2.00
Bristol Royal Hospital for Children	BRC	94.50	98.60	98.75	99.00	99.50	2.35	3.00
Dublin, Our Lady's Children's Hospital	OLS	97.25	94.50	97.00	98.25	99.00	3.00	2.00
Glasgow, Royal Hospital for Sick Children	RHS	98.50	99.25	99.25	99.50	99.50	1.00	2.00
Leeds General Infirmary	LGI	97.00	97. 75	98.00	99.00	98.25	2.00	3.00
Leicester, Glenfield Hospital	GRL	94.00	97.00	97.25	97.00	94.75	1.00	3.00
Liverpool, Alder Hey Children's Hospital	ACH	97.25	95.25	97.50	98.00	98.50	1.80	3.00
London, Evelina London Children's Hospital	GUY	97.50	99.25	96.00	99.00	99.40	3.00	3.00
London, Great Ormond Street Hospital for Children	GOS	99.50	97.00	99.50	95.00	93.00	1.00	2.00
London, Harley Street Clinic	HSC	94.50	95.50	95.75	95.50	**	no information	2.00
London, Royal Brompton Hospital	NHB	99.00	99.25	99.25	99.00	87.50	2.00	3.00
Newcastle, Freeman Hospital	FRE	97.25	97.50	99.00	98.75	99.00	1.00	3.00
Southampton, Wessex Cardiothoracic Centre	SGH	97.50	95.75	99.00	98.75	98.75	1.50	3.00
Adult only Hospitals								
Belfast, Royal Victoria Hospital	RVB	na	na	na	95.00	96.00	0.50	1.00
Birmingham, Queen Elizabeth Hospital	QEB	79.00	75.25	92.50	94.50	87.25	0.60	1.00
Glasgow, Golden Jubilee Hospital	GJH	94.50	92.50	99.00	**	**	1.00	1.00
Liverpool Heart & Chest Hospital	BHL	****	****	****	****	93.50	1.00	1.00
London, University College/St Bartholomew's Hospital	UCL/SBH	94.25	93.25	96.75	96.50	96.60	1.00	1.00
Manchester Royal Infirmary	MRI	97.00	97.70	98.50	***	***	n/a	n/a

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

Whole Time Equivalents (WTE), Data Base Managers (DBM's)

Note: The last two columns in Table 22 show the actual number of Database Managers for each centre comparing with the standards recommended by NHS England.

DQI SUMMARY

The DQI has consistently improved over the last five years, where we have seen an increase in centres reaching over 98% DQI from 2015/16 onwards. This may reflect better investment, specific training and retention of data management staff at centres and some increased engagement from clinical staff.

- Only 1 centre fell below 90% for 3 out of the five years reported (QEB).
- 1 centre consistently reached over 98% over the 5-year period (RHS).2017/18: No data were submitted for 3 centres due to lack of data sharing agreements.
- 2016/17 was a notable year for good data quality. No centres fell below 90%.

OTHER REASONS FOR VARIATION

Failing to invest sufficiently in adequately trained and supported staff to collect and manage the data can influence data quality. NHSE sets out clear guidelines on requirements in the 2016 publication Congenital heart disease standards and specifications.[25]

NCHDA recommend that Database Managers should have a strong clinical background with some basic IT skills. Lack of time invested by local Clinical Leads into the data quality processes may also impact on data quality and completeness as can a general lack of clinician ownership of the data and engagement with data collecting and quality checking. Other factors that may impact data quality are poor investment in the IT infrastructure for instance, to optimise 'point of service' data input/collection by clinicians.

APPENDIX 2: DATA VALIDATION AND DATA QUALITY INDICATOR SCORES

A2.1: DATA QUALITY INDICATOR SCORES – OVERALL, CATHETER AND SURGERY

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%.

Table 23 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, 2016/17 to 2018/19. 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 24. 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 23: *DQI scores for mixed practice and paediatric congenital heart hospitals 2016/17, 2017/18 and 2018/19*

ACHD Hospitals who received on site validation visits														
DQI% for 2016/2017 data based on the 20 case note review					DQI% for 2017/18 data based on the 20 case note review					DQI% for 2018/19 data based on the 20 case note review				
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 Hospital,	RVB	94.5	96.25	94	Belfast Royal Victoria Hospital	RVB	Now commissioned as ACHD only			Belfast Royal Victoria Hospital	RVB	Now commissioned as ACHD only		
Birmingham Children's Hospital	BCH	99.5	100	99.5	Birmingham Children's Hospital	BCH	99	98.75	99	Birmingham Children's Hospital	BCH	99	99.5	98.5
Bristol Royal Hospital for Children	BRC	98.75	99.25	98	Bristol Royal Hospital for Children	BRC	99.00	99.25	99	Bristol Royal Hospital for Children	BRC	99.50	98.75	99.8
Dublin, Our Lady's Children's Hospital,	OLS	97	96.75	97.5	Dublin, Our Lady's Children's Hospital,	OLS	98.25	99	98	Dublin, Our Lady's Children's Hospital,	OLS	99	99.75	98.25
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	Glasgow Royal Hospital for Sick Children,	RHS	99.5	99.75	99.5
Leeds General Infirmary	LGI	98	99	97.5	Leeds General Infirmary	LGI	99	98.25	99.5	Leeds General Infirmary	LGI	98.25	97.75	98.5
Leicester Glenfield Hospital	GRL	97.25	94	98	Leicester Glenfield Hospital	GRL	97	97	94.5	Leicester Glenfield Hospital	GRL	94.75	94.25	96
Liverpool Alder Hey Children's Hospital	ACH	97.5	97	99	Liverpool Alder Hey Children's Hospital	ACH	98	96.25	95	Liverpool Alder Hey Children's Hospital	ACH	98.5	98.75	99
London Evelina London Children's Hospital	GUY	96	94.75	97	London Evelina London Children's Hospital	GUY	99	99.50	98.75	London Evelina London Children's Hospital	GUY	99.3	99.50	98.75
London Great Ormond Street Hospital for Sick Children	GOS	99.5	99.75	98.75	London Great Ormond Street Hospital for Sick Children	GOS	95	95.5	95	London Great Ormond Street Hospital for Sick Children	GOS	93	92.6	95
London Royal Brompton Hospital	NHB	99.25	99.25	98.75	London Royal Brompton Hospital	NHB	99	98	99.25	London Royal Brompton Hospital	NHB	87.5	92.75	80
Newcastle Freeman Hospital	FRE	99	98.25	99	Newcastle Freeman Hospital	FRE	98.75	98.25	99.75	Newcastle Freeman Hospital	FRE	99	99	99
Southampton Wessex Cardiothoracic Centre	SGH	99	99.25	99	Southampton Wessex Cardiothoracic Centre	SGH	98.75	98.25	99	Southampton Wessex Cardiothoracic Centre	SGH	98.75	99.25	97

Table 24: *DQI scores for adult only congenital heart centres which received onsite validation visits*

ACHD Hospitals who received on site validation visits														
DQI% for 2016/2017 data based on the 20 case note review					DQI% for 2017/18 data based on the 20 case note review					DQI% for 2018/19 data based on the 20 case note review				
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 Hospital	**RVB**	95	93.5	96	Belfast Royal Victoria Hospital	**RVB**	96	91.25	99
Birmingham Queen Elizabeth Hospital	**QEB**	92.5	89.75	95.5	Birmingham Queen Elizabeth Hospital	**QEB**	94.5	94.5	79.5	Birmingham Queen Elizabeth Hospital	**QEB**	87.25	87	89.25
Glasgow Golden Jubilee Hospital	**GJH**	99	99	99	Glasgow Golden Jubilee Hospital	**GJH**	Data not submitted in time to be assessed			Glasgow Golden Jubilee Hospital	**GJH**	Data not submitted in time to be assessed		
Liverpool Heart & Chest Hospital	**BHL**	NA	NA	NA	Liverpool Heart & Chest Hospital	**BHL**	NA	NA	NA	Liverpool Heart & Chest Hospital	**BHL**	93.5	92.75	94
London University College / St Bartholomew's Hospital	**UCL/ SBH**	96.75	97.75	96	London University College / St Bartholomew's Hospital	**UCL/ SBH**	96.5	100	96.5	London University College / St Bartholomew's Hospital	**UCL/ SBH**	96.6	99	95.75
Manchester Royal Infirmary	**MRI**	98.5	98	98	Manchester Royal Infirmary	**MRI**	Now Level 2 Service and Remotely Validated			Manchester Royal Infirmary	**MRI**	Now Level 2 Service and Remotely Validated		

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.

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 ASD or 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

Table 25: *Remotely validated adult only congenital heart centres*

Remotely validated adult only congenital heart centres														
April - March 2016/2017					April - March 2017/2018					April - March 2018/2019				
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	Remote validation			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 26: *Non-participating adult only congenital heart centres*

Remotely validated adult only congenital heart centres														
April - March 2016/2017					April - March 2017/2018					April - March 2018/2019				
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	No Data Submitted			Bristol Spire	GHB	No Data Submitted			Glasgow Golden Jubilee	GJH	No Data Submitted		
Cambridge Papworth	PAP	No Data Submitted			Cambridge Papworth	PAP	No Data Submitted							
					Glasgow Golden Jubilee	GJH	No Data Submitted							

APPENDIX 3: 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.
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.

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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 FOR 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 the Welsh Government and, for four of the domains, from the Scottish Government. Funding has been 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 people, 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, The Royal London Hospital in Whitechapel, Newham Hospital in Plaistow, Whipps Cross 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.
www.hqip.org.uk/national-programmes