National Congenital Heart Disease Audit (NCHDA)
Additional detail to the 2020/23 Summary Report

1 Quality Improvement Metrics

1.1 Congenital Heart Disease Procedural Activity

Over 11,000 procedures in children and adults were submitted to the audit in 2022/23. The report focuses on the activity and trends in the treatment of paediatric and adult patients with congenital heart disease (CHD) in the UK and Ireland (not including Scotland which now has its own Scottish Cardiac Audit Programme). The number 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 (i.e. practice makes perfect). Consequently, 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.[1] [2]

1.1.1 Overview of QI metric: Summary of procedures/volume of activity

QI Metric Description/Name	**Procedural activity by age group and each centre Catheter-based and surgical activity**
Why is this important?	Activity standards were set by NHS England in liaison with the Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS) to provide the best opportunity of achieving good outcomes for cardiac procedures in children and adults with CHD.
What is the standard to be met?	NHS England Standards[1] 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 (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 to support the metric	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.[1] Congenital Heart Disease Services: Decision Making Business Case November 2017: Annex B, page 358 (Appendix 1, Annex 6).[3]Error! B ookmark not defined.
Numerator	NHSE countable surgical procedures - for neonate, child and adults.
Denominator	NHSE countable surgical procedures.

1.1.2 Audit results: all Paediatric and ACHD centres

Table 1: All CHD countable procedure volumes by age group, UK and the Republic of Ireland (not including Scotland and excluding one private centre), 2022/23 [NCHDA data]

PROCEDURES 2022/23

Activity	Procedures (All ages)	Procedures (Under 16 years)	Procedures (16 years and older)
Overall activity	11,036	6,911	4,125
Surgical procedure activity	—	—	—
Surgery undertaken using cardiopulmonary bypass	3,367	2,504	863
Surgery undertaken without using cardiopulmonary bypass (including surgical EP)	687	613	74
Hybrid procedures	56	47	9
Primary ECMO	88	84	4
Ventricular Assist Device (VAD)	14	13	<3
Total	**4,212**	**3,261**	**95***
Catheter procedure activity	—	—	—
Interventional catheterisation procedures	3,758	2,134	1,624
Diagnostic catheter procedures	1,364	851	531

Total	**5,116**	**2,985**	**2,155**
Electrophysiological activity (non-surgical)	—	—	—
Implantable Cardioverter Defibrillator (ICD)	156	57	99
Pacemaker procedures	489	103	386
EP ablation and EP diagnostic procedures	1,057	505	552
Total	**1,702**	**665**	**1,037**

***Note**: Activity numbers are those procedures agreed by NHS England to be 'countable' towards individual operator activity. Data in Scottish centres were excluded in the reporting. 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 are considered post-procedural complications).*

*Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable to ensure anonymity of the patient data included in reporting. An * denotes a number between 0 and 9.*

Table 2: Total number of cases categorised by type of procedure submitted to the NCHDA financial years (2013/14-2022/23)

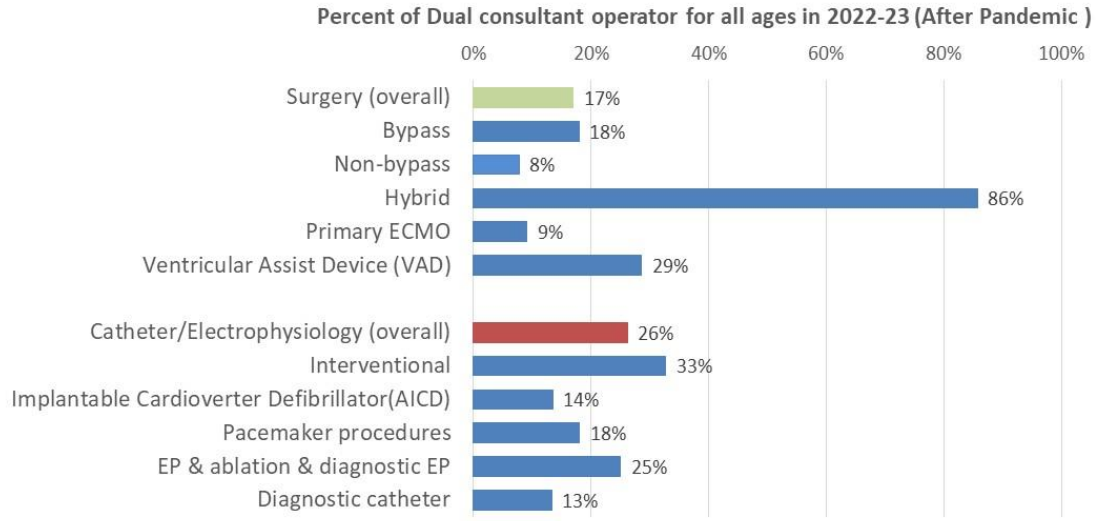
Year	Surgical	Hybrid	EP/PACING	ICD	Intervention	Diagnostic Catheter	Total
2013/14	6,018	49	938	108	3,697	—	10,810
2014/15	5,656	62	1,031	116	3,435	—	10,300
2015/16	5,671	55	1,344	124	3,614	1,737	12,545
2016/17	5,677	48	1,457	155	3,837	1,879	13,053
2017/18	5,376	80	1,440	112	3,673	1,745	12,426
2018/19	5,288	74	1,416	133	3,519	1,634	12,064
2019/20	5,148	84	1,605	164	3,861	1,531	12,393
2020/21	3,894	57	1,288	134	3,174	1,202	9,749
2021/22	4,016	65	1,525	167	3,783	1,333	10,889

2022/23	4,156	56	1,546	156	3,758	1,364	11,036
Total	**50,900**	**630**	**13,590**	**1,369**	**36,351**	**12,425**	**115,265**

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. Data from Scotland centres were not included.

The dual consultant operator data remain constant for different procedure types and age groups [Figure 1.1]. For hybrid procedures, it is important to highlight that discrepancy in data entry by centres (i.e. either the procedure is misclassified as a hybrid or does not involve a consultant operator but a highly trained junior doctor) has led to dual consultant operators for hybrid procedures for all age groups being below the expected 100% (around 80%).

Figure 1.1: Percentage of patients of any age who had their procedure undertaken by two consultant operators, broken down by procedure type, 2020/23



1.2 Summary of 30-day Mortality pertaining to aggregated and specific procedure outcomes, 2020/23

1.2.1 Surgical procedural mortality remains low

Despite CHD being one of the most complex areas for surgery and lifesaving treatment, hospitals providing care for children and adults with CHD have low levels of 30-day mortality. The audit uses two risk models for assessing outcomes:

- Partial Risk Adjustment in Surgery (PRAiS) model for children[4 5]

- Society of Thoracic Surgeons - European Association for Cardio-thoracic Surgery (STAT) mortality score for adults (16 years and over)[6]

1.2.2 Overview of QI metric: Summary of 30-day Mortality pertaining to aggregated and specific procedure outcomes, 2020/23

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 is detected. Exemplary centre level performance can be used as a benchmark for quality improvement initiatives.
What is the standard to be met?	30-day PRAiS2 risk-adjusted mortality at centre level for aggregated surgical procedures in children looking for deviation (positive or negative) from a national average performance. 30-day STAT risk-adjusted mortality at centre level for aggregated surgical procedures in adults with CHD looking for deviation (positive or negative) from a national average performance. 30-day mortality at centre and procedure levels for 84 specific CHD procedures (51 surgical, 23 catheter-based and 10 electrophysiological) looking for negative deviation from a national average performance.
Key references to support the metric	Rogers L, Brown KL, Franklin RC, et al. Improving Risk Adjustment for Mortality After Pediatric Cardiac Surgery: The UK PRAiS2 Model. Ann Thoracic Surg 2017;104(1):211-9[4] Improving risk adjustment in the PRAiS model for mortality after paediatric cardiac surgery and improving public understanding of its use in monitoring outcomes[5] 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[6]
Numerator	Number of patients whose death is recorded by centre or ONS linkage within 30 days of the procedure.
Denominator	Total expected risk-adjusted mortality.

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. This gives improved statistical performance.[4] A further recalibration of the PRAiS model is ongoing.

1.2.3 Audit results: 30-day survival after 84 specific procedures

Survival at thirty days was analysed for 84 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. View the volume and outcomes of activity for the different procedure categories and specific procedures for each congenital heart centre. View the funnel plots for each specific procedure**.**

NICOR follows the Department of Health Outlier Policy,[7] which sets out a process for providing assurance that all hospitals provide the expected quality of care.

1.3 Summary of post-procedural complications

1.3.1 There was some variance between hospitals in rates of post-procedural complications

We recognise that excellent early survival rates supplemented by a wider range of outcome measures help better demonstrate the longer-term clinical and health-economic impact following paediatric and adult congenital heart interventions.[8]

In April 2015, the audit began a process to capture post-procedural complications following surgery and transcatheter interventions (including electrophysiology), to provide more accurate analysis of early morbidities. New robust definitions for these will be introduced as part of collecting the data for next year's report.

View the report of post-procedure complication rates for children (less than 16 years of age) following 3282 surgical procedures, 3,030 transcatheter interventions and 687 electrophysiology procedures at 10 UK and Republic of Ireland centres during 2019/22.

1.3.2 Overview of QI metric: Summary of post-procedural complications

QI Metric Description/Name	**Incidence of six post-procedural complications:** Use of extracorporeal life support Need for renal replacement therapy (including peritoneal dialysis) 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 the 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.

What is the standard to be met?	No standards, but the least possible incidence is optimal, this being dependant on the patient's pre-operative cardiac status. Definitions and measurement of post-procedure continues to be an area of on-going development in the audit.
Key references to support the metric	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[8] 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[9] 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[10]
Numerator	Count of patients with a coded complication.
Denominator	Countable surgical procedures.

1.3.3 Audit results

Error! Reference source not found. demonstrate the rate of four surgical-related and two i nterventional catheter-related across 10 paediatric centres for the period between 2020 and 2023.

Table 3: Incidence of post-surgical use of extracorporeal life support in children (under 16 years of age) at the 10 UK and Republic of Ireland centres (Scottish centres excluded) in 2020/23

Hospital	Centre code	No	Yes	Total	%
Newcastle Freeman Hospital	FRE	471	39	510	7.65
Liverpool Alder Hey Hospital	ACH	946	41	987	4.15
Leicester Glenfield Hospital	GRL	502	20	522	3.83
Birmingham Children's Hospital	BCH	1,077	38	1,115	3.41
London Great Ormond Street Hospital for Children	GOS	1,501	36	1,537	2.34
Dublin Our Lady's Children's Hospital	OLS	920	22	942	2.34
Bristol Royal Hospital for Children	BRC	715	12	727	1.65

Southampton Wessex Cardiothoracic Centre	SGH	731	9	740	1.22
Leeds General Infirmary	LGI	820	9	829	1.09
London Evelina London Children's Hospital	GUY	1,606	15	1,621	0.93
Total	—	**9,289**	**241**	**9,530**	**2.53**

The overall rate of this important and impactful adverse event was 2.53% (range per centre 0.93-7.65): neonatal 5.2% (93/1,775), infant 2.3% (93/4,039), child 1.5% (55/3,716). There is similar centre-related variability to the 2020-23 analyses with highest rates in Newcastle (7.65%) and those with a national ECMO program (Newcastle, Leicester; 3.83 - 7.65%), as shown in Table 3. 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, and in the NCHDA data. Highest post-operative ECMO rates were following repair of common arterial trunk with aortic arch obstruction at 25% (1/4) or without at 9.4% (5/53), heart transplantation at 20.7% (17/82), a Norwood procedure at 15.6% (37/238), and repair of anomalous coronary artery at 13% (6/46).

Table 4: Incidence of post-surgical need for renal replacement therapy (dialysis) in children (under 16 years of age) at the 10 UK and Republic of Ireland centres (Scottish centres excluded) in 2020/23

Hospital	Centre code	No	Yes	Total	%
Bristol Royal Hospital for Children	BRC	672	55	727	7.57
Newcastle Freeman Hospital	FRE	476	34	510	6.67
Leeds General Infirmary	LGI	790	39	829	4.7
London Evelina London Children's Hospital	GUY	1,556	65	1,621	4.01
London Great Ormond Street Hospital for Children	GOS	1,495	42	1,537	2.73
Liverpool Alder Hey Hospital	ACH	962	25	987	2.53
Birmingham Children's Hospital	BCH	1,095	20	1,115	1.79
Southampton Wessex Cardiothoracic Centre	SGH	731	9	740	1.22
Dublin Our Lady's Children's Hospital	OLS	934	8	942	0.85
Leicester Glenfield Hospital	GRL	521	<3	52*	0.19

Total	**—**	**9,232**	**29***	**9,53***	**3.13**

Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable to ensure anonymity of the patient data included in reporting.

The overall rate was 3.13% (range per centre 0.19-7.57%): neonatal 9.63% (171/1,775), infant 1.98% (80/4,039), child 1.26% (47/3,716). Like last year there is considerable inter-centre variability from under 1.0% (Dublin and Leicester) to 6-7% (Newcastle and Bristol), as shown in **Error! Reference source not found.**. This most likely reflects differing intensive c are 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 75% (3/4) or without arch obstruction at 22.64% (12/53), repair of complex transposition with arch obstruction 22.22% (8/36) or without arch obstruction 12.39% (14/113) in 20% of cases having a Norwood procedure 22.69% (54/238) or lung transplant 20% (1/5) and repair of total anomalous pulmonary venous connection at 6.52% (3/46).

Table 5: Unplanned placement of a pacemaker at the 10 UK and Republic of Ireland centres (Scottish centres excluded) in 2020/23

Hospital	Centre code	No	Yes	Total	%
Dublin Our Lady's Children's Hospital	OLS	918	24	942	2.55
Bristol Royal Hospital for Children	BRC	714	13	727	1.79
Newcastle Freeman Hospital	FRE	501	9	510	1.76
Leeds General Infirmary	LGI	816	13	829	1.57
Liverpool Alder Hey Hospital	ACH	973	14	987	1.42
Southampton Wessex Cardiothoracic Centre	SGH	731	9	740	1.22
Birmingham Children's Hospital	BCH	1,102	13	1,115	1.17
London Great Ormond Street Hospital for Children	GOS	1,524	13	1,537	0.85

London Evelina London Children's Hospital	GUY	1,608	13	1,621	0.8
Leicester Glenfield Hospital	GRL	519	3	522	0.57
Total	—	**9,406**	**124**	**9,530**	**1.3**

Overall, there were 124 cases with a somewhat reassuringly low rate of 1.3% (range per centre 0.57-2.55%): neonatal 0.51% (9/1,775), infant 1.39% (56/4,039), child 1.59% (59/3,716).

There was some inter-centre variability in Table 5, 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 13.79% (4/29), and tricuspid (14.29%, 2/14) or mitral valve replacement (13.73%, 14/102).

Table 6: Incidence of post-surgical prolonged pleural drainage (over 7-10 days) in children (under 16 years of age) at the 10 UK and Republic of Ireland centres (Scottish centres excluded) in 2020/23

Hospital	Centre code	No	Yes	Total	%
Dublin Our Lady's Children's Hospital	OLS	911	31	942	3.29
Birmingham Children's Hospital	BCH	1,080	35	1,115	3.14
Bristol Royal Hospital for Children	BRC	707	20	727	2.75
Leeds General Infirmary	LGI	812	17	829	2.05
London Great Ormond Street Hospital for Children	GOS	1,508	29	1,537	1.89
Southampton Wessex Cardiothoracic Centre	SGH	731	9	740	1.22
Liverpool Alder Hey Hospital	ACH	977	10	987	1.01
London Evelina London Children's Hospital	GUY	1,605	16	1,621	0.99
Newcastle Freeman Hospital	FRE	506	4	510	0.78
Leicester Glenfield Hospital	GRL	519	3	522	0.57

Total	—	**9,356**	**174**	**9,530**	**1.83**

Overall, there were 174 cases with a rate of 1.83% (range per centre 0.57-3.29): neonatal 1.41% (25/1,775); infant 1.71% (69/4,039), child 2.15% (80/3,716). There were again clear differences between centres with highest rates at Dublin (3.29%) and Birmingham (3.14%), as shown in **Error! Reference source not found.**5, requiring more detailed case by case r eview, given that certain procedures are expected to be at much higher risk for this complication, such as Fontan-type procedures (13.51%; 52/385), as well as Rastelli procedure (6.12%, 3/49). As of last year, the Congenital Audit has changed the definition to be greater than 10 days of drainage to be in line with the definitions used by the national Congenital Heart Services Quality Dashboard.

Table 7: Incidence of post-surgical need for unplanned reintervention in children (under 16 years of age) at the 10 UK and Republic of Ireland centres (Scottish centres excluded) in 2020/23

Hospital	Centre code	No	Yes	Total	%
Liverpool Alder Hey Hospital	ACH	843	10	853	1.17
Birmingham Children's Hospital	BCH	770	8	778	1.03
Bristol Royal Hospital for Children	BRC	635	5	640	0.78
Newcastle Freeman Hospital	FRE	813	5	818	0.61
London Great Ormond Street Hospital for Children	GOS	488	3	491	0.61
Leicester Glenfield Hospital	GRL	1,335	8	1,343	0.6
London Evelina London Children's Hospital	GUY	1,554	8	1,562	0.51
Leeds General Infirmary	LGI	619	<3	62*	0.32
Dublin Our Lady's Children's Hospital	OLS	317	<3	31*	0.31
Southampton Wessex Cardiothoracic Centre	SGH	721	<3	72*	0.14
Total	—	**8,095**	**5***	**8,14***	**0.63**

Data are suppressed where case numbers are less than three and secondary suppression has been applied where applicable to ensure anonymity of the patient data included in reporting.

Overall, there were around 50 cases with, again, a reassuringly low rate of 0.63% (range per centre 0.14-1.17): neonatal 2.17% (19/876), infant 1.10% (19/1,728), child 0.23% (13/5,542) in Table 7.

Most frequent procedures were not surprisingly neonatal radiofrequency pulmonary valve perforation-dilation (3 of 38 cases, 7.89%), as both procedures may involve inadvertent perforation of the right ventricular or pulmonary outflow tracts.

Table 8: Incidence of catheter-related device embolisation following or during a transcatheter procedure in children (under 16 years of age) at the 10 UK and Republic of Ireland centres (Scottish centres excluded) in 2020/23

Hospital	Centre code	No	Yes	Total	%
London Evelina London Children's Hospital	GUY	1,544	18	1,562	1.15
Birmingham Children's Hospital	BCH	809	9	818	1.1
Newcastle Freeman Hospital	FRE	486	5	491	1.02
Dublin Our Lady's Children's Hospital	OLS	1,331	12	1,343	0.89
Leeds General Infirmary	LGI	846	7	853	0.82
Liverpool Alder Hey Hospital	ACH	772	6	778	0.77
London Great Ormond Street Hospital for Children	GOS	718	4	722	0.55
Southampton Wessex Cardiothoracic Centre	SGH	618	3	621	0.48
Bristol Royal Hospital for Children	BRC	640	0	640	0
Leicester Glenfield Hospital	GRL	318	0	318	0
Total	—	**8,082**	**64**	**8,146**	**0.79**

Overall, there were 64 cases with, again, a reassuringly low rate of 0.79% (range per centre 0-1.15): neonatal 1.6% (14/876), infant 1.39% (24/1,728), child 0.47 (26/5,542). There was some inter-centre variability likely reflecting case complexity in Table 8, but also possibly the increasing use of the transcatheter route for closing a patent arterial duct in prematurely born neonates and infants (3.18%; 17/534).

There is variation between centres in all of these complications. For example, renal support was used more frequently in some centres than others, ECMO is used more often in established ECMO centres. A working group of the NCHDA has completed review of the definitions of all complications. New robust definitions have been introduced in 2023 and will be used as part of collecting the data for next year's report.

1.4 Summary of level of antenatal diagnosis

1.4.1 There was a slight drop in rates of antenatal diagnosis

About 20–30% of congenital heart defects are severe, defined as being potentially life threatening and requiring surgery within the first year of life.[11] [12] 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.[13] Poor antenatal diagnosis rates also limits the opportunity to counsel expectant patients.[14]

Consequently, a goal of CHD services is to diagnose heart disease as early as possible and ideally before birth (referred to as antenatal diagnosis). The audit collects data for babies diagnosed antenatally with a cardiac defect who then undergoes an intervention in the first year of life, described as Procedures with Prenatal Diagnosis (PPD). As such, these data do not represent the 'true' antenatal detection rates, since they exclude spontaneous intrauterine deaths, termination of pregnancy, non-intervention after birth and unrecognised death in community or non-tertiary centre.

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 a PPD rate of at least 75% for all abnormalities. Further discussion is required to determine whether different realistically achievable targets are needed for specific lesions. With considerable regional variations in diagnostic rates, the audit has used regional Integrated Care System (ICS) boundaries to map PPD rates.[15]

1.4.2 Overview of QI metric: 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.

What is the standard to be met?	National fetal cardiology group recommendation for sonographers to: Achieve diagnosis PPD rate of at least 75% for all abnormalities where an intervention is undertaken in the first year of life; Achieve a high PPD rate of at least 90% for certain specific lesions where an intervention within hours of birth may be required.
Key references to support the metric	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.[13] 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.[14]
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. It is important to highlight the denominator does not include spontaneous intrauterine deaths, termination of pregnancy, non-intervention after birth and unrecognised death in community or non-tertiary centres and numbers may differ depending on the type of cardiac lesion.

1.4.3 Audit Results: Overall detection of infants requiring a procedure

Over the last five years, the rate of antenatal diagnosis seems to have stabilised at just over 50%. The detection rate was 54.1% for all infants requiring a procedure in the first year of life improved when compared to 2021/22. There is considerable variability within the UK of antenatal detection, and until the lower performing regions improve, it will be difficult to increase overall percentage diagnosed prenatally. While there has been a drop since the COVID-19 pandemic, prenatal screening continued throughout the pandemic. It is important to note that most CHD cases are detected in the low-risk screening population and therefore the PPD detection rate is determined by the screening hospitals and not by CHD centres.

We have demonstrated the national variation of antenatal diagnosis rates in 2022/23 for infants who underwent a procedure in the first year of life for any cardiac malformation in the UK and Republic of Ireland using ICS mapping (Scottish centres not included).

With considerable regional variations in diagnostic rates, the audit has used regional Integrated Care System (ICS) boundaries to map PPD rates.[15]

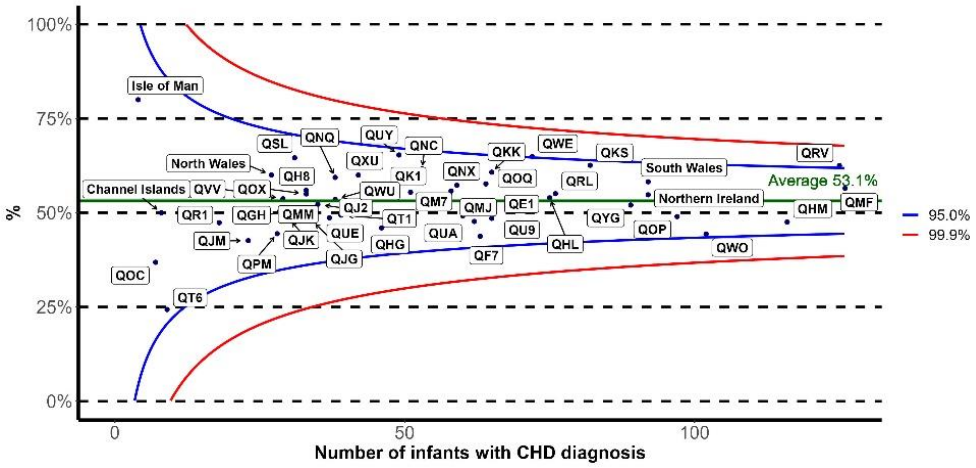
To understand and improve rates of detection and reduce regional variation, several steps should be considered:

- Agreement on which pregnancies should undergo more detailed fetal echocardiography, to reduce variation in referral criteria

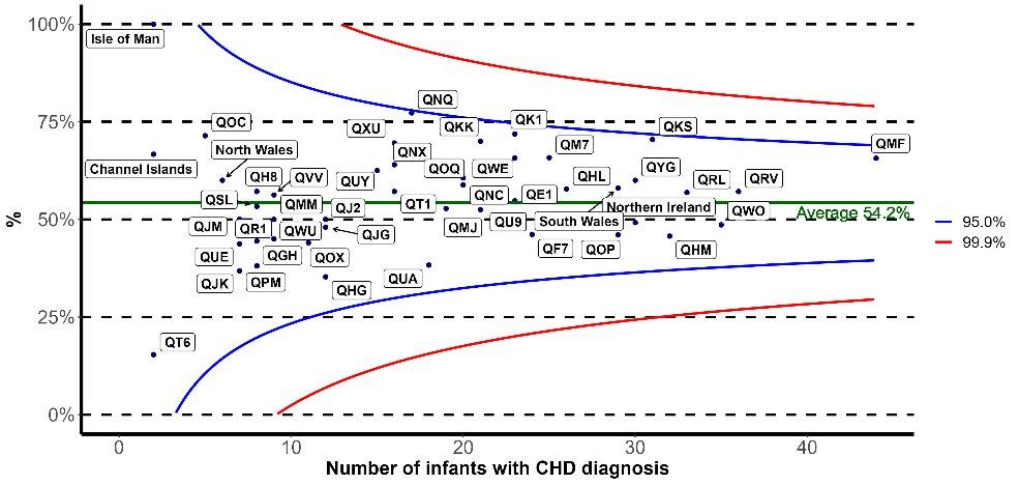
- Mandatory training of the sonographers especially focusing on the 3-vessel and trachea (3VT) view
- Storage of specific cardiac views to allow internal and external review to encourage a learning process and standardised pathways for feedback.

The NCHDA and its sponsoring professional societies will work with commissioners and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) on these matters and to advise regions on steps to be taken to improve performance.

Figure 1.2: Overall PPD rates by region for (a) 2020/23 and (b) 1-year overall PPD rates by region, 2022/23 [NCHDA data]



(a)



(b)

1.4.4 Detection rates for individual cardiac malformations

Tables 9 to 12 show the detection rate of four individual cardiac lesions with breakdown by regional ICS. Figure 1.3, Figure 1.4, Figure 1.5, Figure 1.6 demonstrate the funnel plots for the 4 cardiac lesions.

Table 9: HLHS diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2020/23 in the UK and RoI (Scottish data excluded)

ICB	Total	HLHS diagnosis	% Antenatally diagnosed
England	148	130	87.8
Northern Ireland	7	7	100
Wales	8	8	100
QE1. Healthier Lancashire and South Cumbria	4	4	100
QF7. South Yorkshire and Bassetlaw	7	4	57.1
QGH. Herefordshire and Worcestershire	3	3	100
QH8. Mid and South Essex	<3	<3	100
QHG. Bedfordshire, Luton, and Milton Keynes	4	3	75
QHL. Birmingham and Solihull	6	5	83.3
QHM. Cumbria and North East	7	6	85.7
QJ2. Joined Up Care Derbyshire	3	3	100
QJG. Suffolk and North East Essex	<3	<3	≤66.7
QJK. Devon	<3	<3	100
QJM. Lincolnshire	3	3	100
QK1. Leicester, Leicestershire, and Rutland	6	6	100
QKK. Our Healthier South East London	5	5	100
QKS. Kent and Medway	6	5	83.3
QM7. Hertfordshire and West Essex	3	3	100
QMF. East London Health and Care Partnership	5	5	100
QMJ. North London Partners in Health and Care	3	<3	≤66.7
QMM. Norfolk and Waveney Health and Care Partnership	<3	<3	≤66.7
QNC. Staffordshire and Stoke on Trent	5	5	100
QNQ. Frimley Health and Care ICS	<3	<3	≤66.7

QNX. Sussex and East Surrey Health and Care Partnership	<3	<3	100
QOC. Shropshire, Telford, and Wrekin	<3	<3	100
QOP. Greater Manchester Health and Social Care Partnership	10	10	100
QOQ. Humber, Coast and Vale	5	4	80
QR1. Gloucestershire	3	3	100
QRL. Hampshire and the Isle of Wight	<3	<3	100
QRV. North West London Health and Care Partnership	7	7	100
QT1. Nottingham and Nottinghamshire Health and Care	<3	<3	100
QT6. Cornwall and the Isles of Scilly Health and Social Care Partnership	<3	<3	100
QU9. Buckinghamshire, Oxfordshire, and Berkshire West	4	<3	≤75
QUA. The Black Country and West Birmingham	5	5	100
QUE. Cambridgeshire and Peterborough	<3	<3	100
QUY. Bristol, North Somerset, and South Gloucestershire	5	5	100
QVV. Dorset	<3	<3	100
QWE. South West London Health and Care Partnership	3	3	100
QWO. West Yorkshire and Harrogate (Health and Care Partnership)	6	5	83.3
QWU. Coventry and Warwickshire	<3	<3	100
QYG. Cheshire and Merseyside	7	5	71.4
North Wales	0	0	
South Wales	8	8	100
Total	**163**	**145**	**89.0**

Table 10: TGA-IVS diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2020/23 in the UK and RoI (Scottish data excluded)

ICB	Total	TGA-IVS diagnosis	% Antenatally diagnosed
England	149	117	78.5
Northern Ireland	<3	<3	100
Wales	4	4	100
QE1. Healthier Lancashire and South Cumbria	<3	<3	100
QF7. South Yorkshire and Bassetlaw	10	8	80
QGH. Herefordshire and Worcestershire	<3	<3	100
QH8. Mid and South Essex	<3	<3	100
QHG. Bedfordshire, Luton, and Milton Keynes	6	<3	≤50
QHL. Birmingham and Solihull	5	5	100
QJ2. Joined Up Care Derbyshire	3	3	100
QJG. Suffolk and North East Essex	5	4	80
QJK. Devon	<3	<3	100
QJM. Lincolnshire	<3	<3	100
QKK. Our Healthier South East London	<3	<3	100
QKS. Kent and Medway	3	3	100
QM7. Hertfordshire and West Essex	6	5	83.3
QMF. East London Health and Care Partnership	7	7	100
QMJ. North London Partners in Health and Care	8	6	75
QMM. Norfolk and Waveney Health and Care Partnership	6	5	83.3
QNC. Staffordshire and Stoke on Trent	<3	<3	100
QNQ. Frimley Health and Care ICS	<3	<3	100
QNX. Sussex and East Surrey Health and Care Partnership	<3	<3	100

QOP. Greater Manchester Health and Social Care Partnership	11	5	45.5
QOQ. Humber, Coast and Vale	6	4	66.7
QPM. Northamptonshire	3	<3	≤66.7
QR1. Gloucestershire	<3	<3	100
QRL. Hampshire and the Isle of Wight	<3	<3	100
QRV. North West London Health and Care Partnership	5	5	100
QT1. Nottingham and Nottinghamshire Health and Care	3	<3	≤66.7
QUA. The Black Country and West Birmingham	8	6	75
QUE. Cambridgeshire and Peterborough	3	<3	≤66.7
QVV. Dorset	<3	<3	100
QWE. South West London Health and Care Partnership	4	4	100
QWO. West Yorkshire and Harrogate (Health and Care Partnership)	12	8	66.7
QWU. Coventry and Warwickshire	<3	<3	100
QXU. Surrey Heartlands Health and Care Partnership	3	3	100
QYG. Cheshire and Merseyside	12	8	66.7
North Wales	<3	<3	100
South Wales	<3	<3	100
Total	**155**	**123**	**79.4**

Table 11: COMPLETE AVSD diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2020/23 in the UK and RoI (Scottish data excluded)

ICB	Total	AVSD COMPLETE diagnosis	% Antenatally diagnosed
Channel Islands	<3	<3	≤66.7
Isle of Man	<3	<3	100
England	269	153	56.9
Northern Ireland	17	10	58.8
Wales	10	7	70
QE1. Healthier Lancashire and South Cumbria	10	6	60
QF7. South Yorkshire and Bassetlaw	11	3	27.3
QGH. Herefordshire and Worcestershire	<3	<3	100
QH8. Mid and South Essex	3	<3	≤66.7
QHG. Bedfordshire, Luton, and Milton Keynes	<	<	≤66.7
QHL. Birmingham and Solihull	10	4	40
QHM. Cumbria and North East	11	7	63.6
QJ2. Joined Up Care Derbyshire	<3	<3	≤66.7
QJG. Suffolk and North East Essex	<3	<3	100
QJK. Devon	3	<3	≤66.7
QJM. Lincolnshire	5	3	60
QK1. Leicester, Leicestershire, and Rutland	6	4	66.7
QKK. Our Healthier South East London	<3	<3	≤66.7
QKS. Kent and Medway	3	<3	≤66.7
QM7. Hertfordshire and West Essex	5	3	60
QMF. East London Health and Care Partnership	18	13	72.2
QMJ. North London Partners in Health and Care	8	4	50
QMM. Norfolk and Waveney Health and Care Partnership	<3	<3	100
QNC. Staffordshire and Stoke on Trent	4	3	75
QNQ. Frimley Health and Care ICS	3	3	100

QNX. Sussex and East Surrey Health and Care Partnership	9	5	55.6
QOC. Shropshire, Telford, and Wrekin	3	0	0
QOP. Greater Manchester Health and Social Care Partnership	14	5	35.7
QOQ. Humber, Coast and Vale	8	5	62.5
QOX. Bath and North East Somerset, Swindon, and Wiltshire	5	3	60
QPM. Northamptonshire	3	<3	≤66.7
QR1. Gloucestershire	<3	<3	100
QRL. Hampshire and the Isle of Wight	8	5	62.5
QRV. North West London Health and Care Partnership	12	8	66.7
QSL. Somerset	5	3	60
QT1. Nottingham and Nottinghamshire Health and Care	9	5	55.6
QT6. Cornwall and the Isles of Scilly Health and Social Care Partnership	3	<3	≤66.7
QU9. Buckinghamshire, Oxfordshire, and Berkshire West	10	4	40
QUA. The Black Country and West Birmingham	5	3	60
QUE. Cambridgeshire and Peterborough	4	3	75
QUY. Bristol, North Somerset, and South Gloucestershire	<3	<3	100
QVV. Dorset	5	4	80
QWE. South West London Health and Care Partnership	7	5	71.4
QWO. West Yorkshire and Harrogate (Health and Care Partnership)	21	9	42.9
QWU. Coventry and Warwickshire	6	5	83.3
QXU. Surrey Heartlands Health and Care Partnership	5	3	60
QYG. Cheshire and Merseyside	14	8	57.1
North Wales	5	4	80
South Wales	5	3	60
Total	**299**	**172**	**57.5**

Table 12: FALLOT diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2020/23 in the UK and RoI (Scottish data excluded)

ICB	Total	FALLOT diagnosis	% Antenatally diagnosed
Channel Islands	3	3	100
England	414	308	74.4
Northern Ireland	13	11	84.6
Wales	16	13	81.3
QE1. Healthier Lancashire and South Cumbria	11	4	36.4
QF7. South Yorkshire and Bassetlaw	13	8	61.5
QGH. Herefordshire and Worcestershire	3	3	100
QH8. Mid and South Essex	7	4	57.1
QHG. Bedfordshire, Luton, and Milton Keynes	7	7	100
QHL. Birmingham and Solihull	14	9	64.3
QHM. Cumbria and North East	22	12	54.5
QJ2. Joined Up Care Derbyshire	6	6	100
QJG. Suffolk and North East Essex	7	6	85.7
QJK. Devon	8	5	62.5
QJM. Lincolnshire	7	4	57.1
QK1. Leicester, Leicestershire, and Rutland	16	12	75
QKK. Our Healthier South East London	12	10	83.3
QKS. Kent and Medway	11	10	90.9
QM7. Hertfordshire and West Essex	15	10	66.7
QMF. East London Health and Care Partnership	20	16	80
QMJ. North London Partners in Health and Care	10	5	50
QMM. Norfolk and Waveney Health and Care Partnership	5	<3	≤60
QNC. Staffordshire and Stoke on Trent	7	5	71.4
QNQ. Frimley Health and Care ICS	4	3	75
QNX. Sussex and East Surrey Health and Care Partnership	8	7	87.5
QOC. Shropshire, Telford, and Wrekin	<3	<3	100
QOP. Greater Manchester Health and Social Care Partnership	21	12	57.1

QOQ. Humber, Coast and Vale	7	6	85.7
QOX. Bath and North East Somerset, Swindon, and Wiltshire	5	5	100
QPM. Northamptonshire	6	4	66.7
QR1. Gloucestershire	4	3	75
QRL. Hampshire and the Isle of Wight	17	16	94.1
QRV. North West London Health and Care Partnership	12	11	91.7
QSL. Somerset	9	9	100
QT1. Nottingham and Nottinghamshire Health and Care	4	4	100
QT6. Cornwall and the Isles of Scilly Health and Social Care Partnership	3	<3	≤66.7
QU9. Buckinghamshire, Oxfordshire, and Berkshire West	20	16	80
QUA. The Black Country and West Birmingham	7	5	71.4
QUE. Cambridgeshire and Peterborough	12	8	66.7
QUY. Bristol, North Somerset, and South Gloucestershire	7	6	85.7
QVV. Dorset	5	4	80
QWE. South West London Health and Care Partnership	14	14	100
QWO. West Yorkshire and Harrogate (Health and Care Partnership)	22	13	59.1
QWU. Coventry and Warwickshire	5	5	100
QXU. Surrey Heartlands Health and Care Partnership	7	6	85.7
QYG. Cheshire and Merseyside	13	11	84.6
North Wales	5	4	80
South Wales	11	9	81.8
Total	**446**	**335**	**75.1**

Figure 1.3: Hypoplastic left heart syndrome (HLHS) in 2020/23

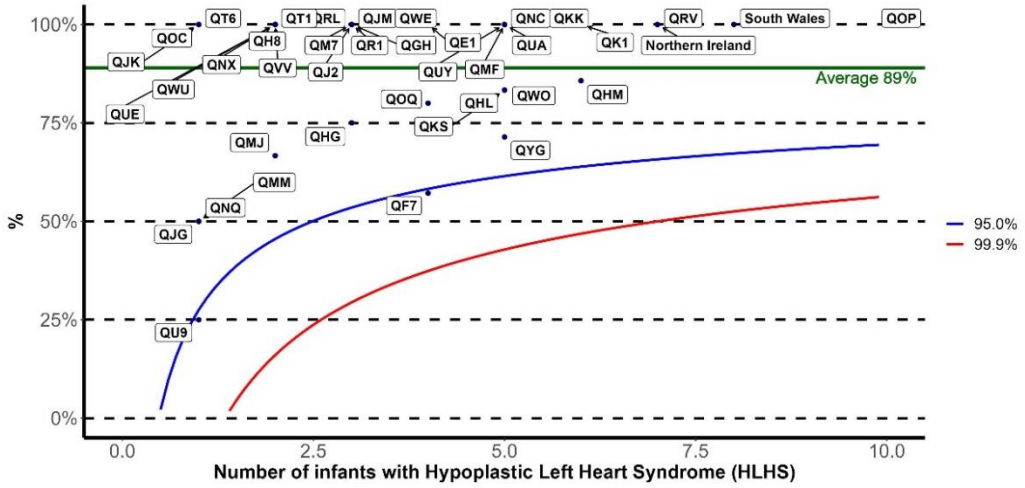


Figure 1.4: Transposition of the great arteries with intact ventricular septum (TGA-IVS) in 2020/23

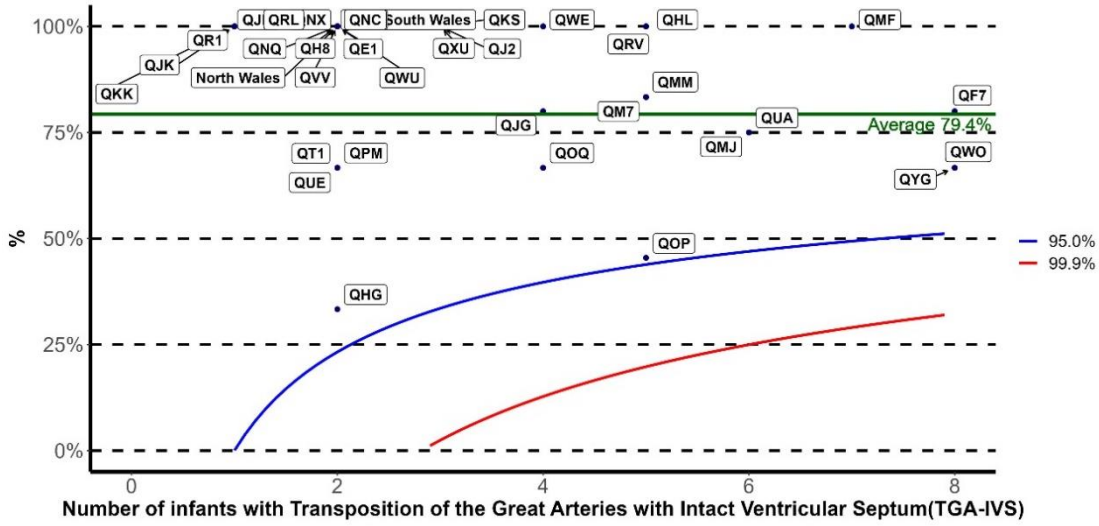


Figure 1.5: Complete atrioventricular septal defect (cAVSD) in 2020/23

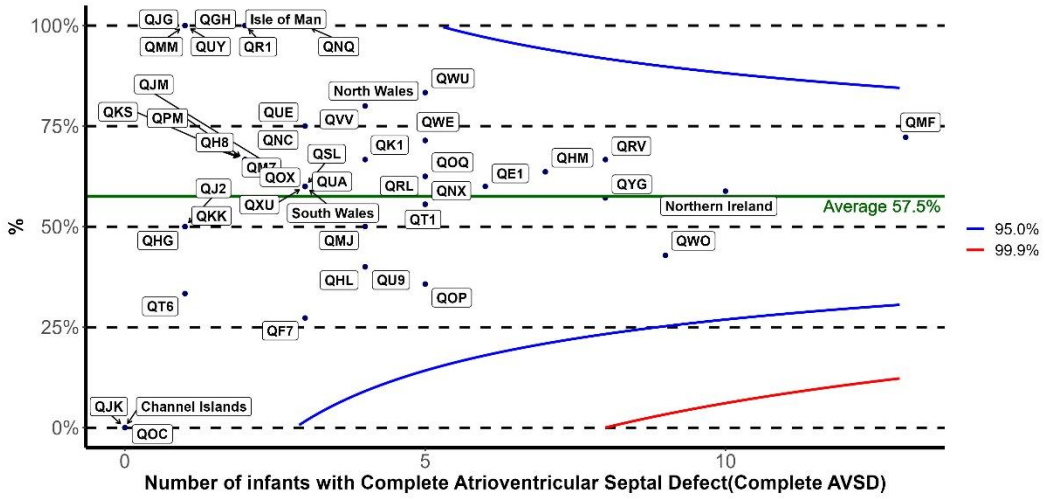
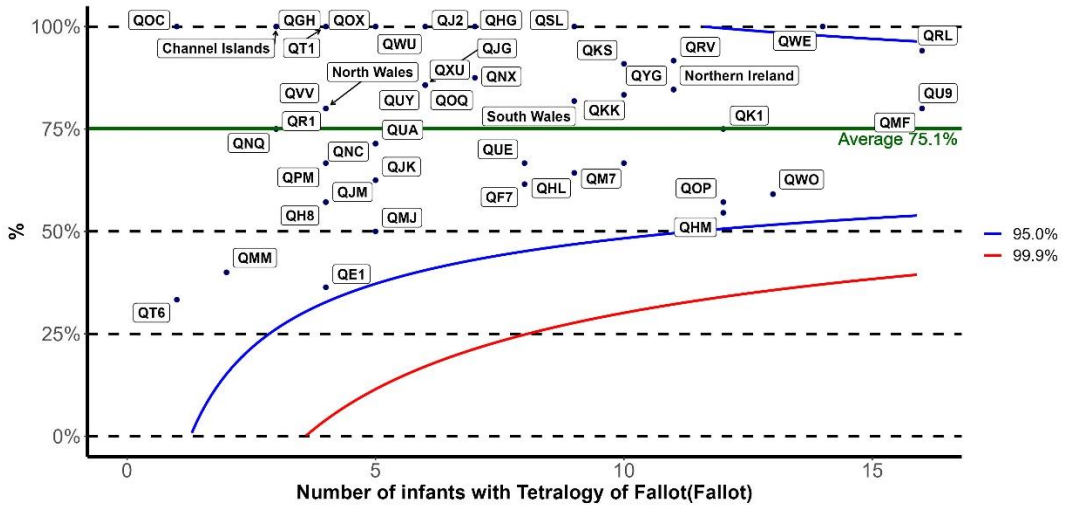


Figure 1.6: Tetralogy of Fallot (TOF) in 2020/23



1.5 Data Quality Indicator (DQI)

The NCHDA validation includes a remote site validation process, which involves on-site assessment of data quality across four 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.

Overall DQI scores remain very good. It is recommended that each Level 1 provider of congenital cardiac services meets the recommended staffing levels specified in NHSE New CHD Review 2016.[1]

1.5.1 Overview of QI Metric: DQI Scoring

QI Metric Description/Name	Data Quality Indicator Score
Why is this important?	Data Quality Indicator score gives an indication of the quality of the data submitted by each centre against defined NCHDA Standard
What is the standard to be met?	Good quality = >90% Excellent quality = >98%
Key references to support the metric	NCHDA annual reports 2018 and 2019. The conceptual basis for this DQI is explained in the 1998 -1999 Data Quality Indicator Methodology Paper (DoH). 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[16] https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-Heart-Disease-Standards-Level-1-Specialist-Surgical-Centres-Adult.pdf[1]
Numerator	Depends on number of procedures the random sample patients have had within a 12-month period – it can range from 20 - 35 procedures depending on complexity of sample.
Denominator	Depends on number of procedures the random sample patients have had within a 12-month period – it can range from 20 - 35 procedures depending on complexity of sample.

Table 13: Data quality indicator score by hospital, 2015/16 – 2022/23

		DQI 2016 - 2023							
Paediatric/Mixed Practice Hospitals	**Code**	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21	2021-22	2022-23
Belfast Royal Victoria	RVB	98.25	94.50	*	*	*	*	*	*
Birmingham Children's Hospital	BCH	97.75	99.50	99.00	99.00	99.00	99.50	99.50	99.50
Bristol Royal Children's Hospital	BRC	98.60	98.75	99.00	99.50	99.25	99.50	99.75	99.50
Dublin, Our Lady's Hospital	OLS	94.50	97.00	98.25	99.00	99.00	98.50	99.25	99.50
Leeds General Infirmary	LGI	97. 75	98.00	99.00	98.25	99.00	99.00	99.25	99.60
Leicester Glenfield Hospital	GRL	97.00	97.25	97.00	94.75	94.75	94.50	96.00	97.75
Liverpool Alder Hey Childrens Hospital	ACH	95.25	97.50	98.00	98.50	98.50	99.50	99.25	99.75
London Evelina Childrens Hospital	GUY/GSTT	99.25	96.00	99.00	99.40	97.75	98.75	99.75	98.50
London Great Ormond Street	GOS	97.00	99.50	95.00	93.00	97.75	98.50	99.25	97.00
London Harley Street Clinic	HSC	95.50	95.75	95.50	**	**	**	**	**
London Royal Brompton & Harefield	NHB	99.25	99.25	99.00	87.50	95.75	98.00	94.75	*****
Newcastle Freeman	FRE	97.50	99.00	98.75	99.00	99.75	99.80	99.50	99.75
Southampton Wessex Cardiothoracic Centre	SGH	95.75	99.00	98.75	98.75	98.25	98.75	98.25	97.75
Adult only Hospitals									
Belfast Royal Victoria	RVB	na	na	95.00	96.00	96.75	98.00	98.75	99.25
Birmingham Queen Elizabeth Hospital	QEB	75.25	92.50	94.50	87.25	95.25	97.00	96.25	97.00
Liverpool Heart & Chest Hospital	BHL	****	****	****	93.50	94.75	98.75	99.25	98.75
London University College/St Bartholomew's	UCL/SBH	93.25	96.75	96.50	96.60	98.00	97.50	98.00	98.25
Manchester Royal Infirmary	MRI	97.70	98.50	***	***	***	***	***	***

* ACHD only	<90
** No data submitted	90 to <95
*** Service transferred	95 to <98
**** New Service	>=98
***** Merged Service NHB + GUY	

2 Annex A: List of codes for participating centres 2021/23

Code	Paediatric and Mixed Practice Hospitals
ACH	Alder Hey Children's Hospital, Liverpool
BCH	Birmingham Children's Hospital
BRC	Bristol Royal Hospital for Children
FRE	Freeman Road Hospital, Newcastle
GOS	Great Ormond Street Hospital for Children, London
GRL	Glenfield Hospital, Leicester
GSTT	Evelina London Children's Hospital, London and Royal Brompton Hospital, London
LGI	Leeds General Infirmary
OLS	Our Lady's Children's Hospital, Dublin
SGH	Wessex Cardiothoracic Centre, Southampton General Hospital

Code	Adult centres
BHL	Liverpool Heart and Chest Hospital
HAM	Hammersmith Hospital, London
MRI	Manchester Royal Infirmary
NCR	Wolverhampton Lung & Heart Centre, New Cross Hospital
NGS	Northern General Hospital, Sheffield
PAP	Papworth Hospital, Cambridge
QEB	Queen Elizabeth Hospital, Birmingham
RAD	John Radcliffe Hospital, Oxford
RSC	Royal Sussex County Hospital, Brighton
RVB	Royal Victoria Hospital, Belfast
SBH	Barts Heart Centre, St Bartholomew's Hospital, London
STO	University Hospital of North Staffordshire, Stoke
UHW	University Hospital of Wales, Cardiff
VIC	Royal Victoria Hospital, Blackpool

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Please go to www.nicor.org.uk for more information.

Email: nicor.auditenquiries@nhs.net

This report is available online via the NICOR website.

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National Institute of Cardiovascular Outcomes Research (NICOR)

NICOR is a partnership of clinicians, IT experts, statisticians, academics and managers who, together, are responsible for the National Cardiac Audit Programme (NCAP) and a number of health technology registries, including the UK TAVI registry. Hosted by Arden & GEM CSU, NICOR collects, analyses and interprets vital cardiovascular data into relevant and meaningful information to promote sustainable improvements in patient well-being, safety and outcomes. NICOR is funded by NHS England and GIG Cymru (NHS Wales).

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Society of Cardiothoracic Surgeons in Great Britain & Ireland

The 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.

www.scts.org

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.

NHS Arden and GEM

NHS Arden & GEM is a Commissioning Support Unit (CSU) working across the health and care sector in England to provide a range of services including procurement and contracting, service transformation, business intelligence, business support and clinical support. Its ability to draw upon expertise from over 1000 staff, working in multidisciplinary teams, enables the CSU to help healthcare commissioners and providers navigate and implement the change needed to improve patient care and outcomes. Arden & GEM's clients include more than 70 customers including Integrated Care Boards, NHS England, Integrated Care Systems, Primary Care Networks, NHS provider trusts and local authorities.

www.ardengemcsu.nhs.uk

NHS England

NHS England leads the National Health Service (NHS) in England. NHS England provides national leadership for the NHS. Through the NHS Long Term Plan, we promote high quality health and care for all, and support NHS organisations to work in partnership to deliver better outcomes for our patients and communities, at the best possible value for taxpayers and to continuously improve the NHS. We are working to make the NHS an employer of excellence and to enable NHS patients to benefit from world-leading research, innovation and technology.

GIG Cymru (NHS Wales)

NHS Wales is the public funded National Health Service of Wales providing healthcare to some 3 million people who live in the country. The Welsh Government sets the Health Care strategy and NHS in Wales delivers that strategy and services via the seven Local Health Boards, three NHS Trusts and two Special Health Authorities. The NHS has a key principle which is that good healthcare should be available to all.

Endnotes

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