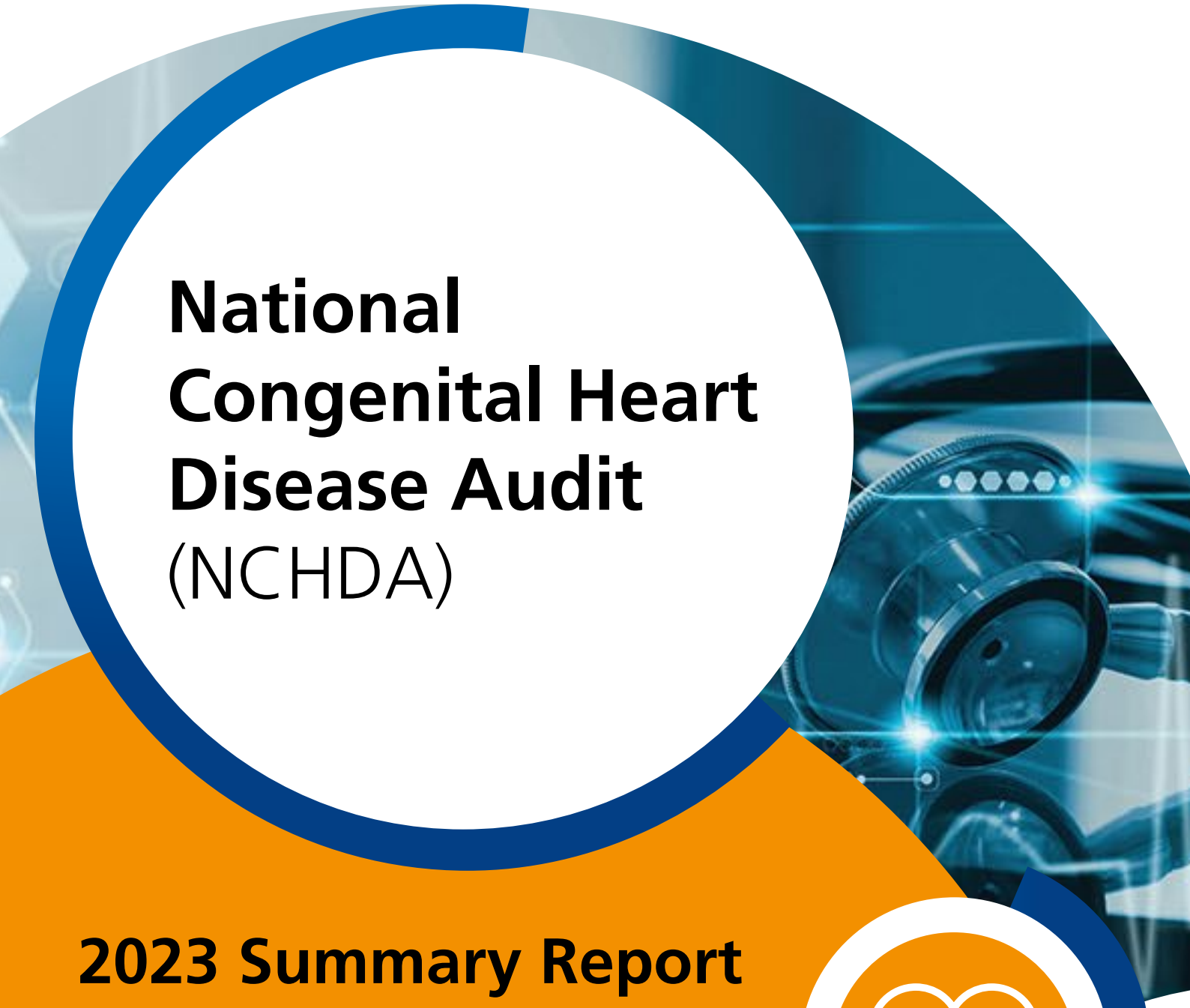
National Cardiac
Audit Programme

NICOR



# National Congenital Heart Disease Audit (NCHDA)

## 2023 Summary Report

(2019/20 – 2021/22)

# Contents

# Report at a glance

Data from the period April 2021 to March 2022

**The impact of COVID-19 on the care of paediatric and adult congenital heart disease patients continues as we recover from the impact of the pandemic. Waiting lists continue to worsen for elective procedures.**

## Number of treatments

There was a **12% increase in overall activity** (surgery, intervention and electrophysiology) with a total of **10,889 congenital heart disease procedures** on children and adults in 2021/22. This is still **8%** fewer compared to 2019/20.

The number of **surgical procedures on children continued to fall,** with **3%** fewer surgical procedures compared to 2020/21 and **15%** down on figures from 2019/20.

## Survival at 30 days

**Despite this being one of the most complex areas of surgery, the UK and Republic of Ireland continue to have excellent outcomes with high survival and low mortality rates.**

Outcomes after **paediatric cardiac surgery** continue to show a high 30-day survival rate of over **98%.**

Overall, **30-day mortality rate** dropped to **1.6%** for both children and adults, slightly lower than the predicted risk rate, showing outcomes are better than expected.

There were approximately **9% fewer deaths** than predicted after 30 days for 2019/20 to 2021/22 after 2120 adult congenital heart disease operations.

## Complications after surgical procedures

**Post-procedure related complication rates for under-16s show some inter-centre variation.**

**Average complication rates include: 2.29%** requiring life support, **1.2%** requiring an unplanned pacemaker, **3.02%** with prolonged pleural drainage and **3.38%** needing renal replacement therapy (including peritoneal dialysis).

## 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.**

**Antenatal diagnosis** for all infants requiring a procedure in the first year of life dropped slightly to **50.4%** in 2021/22, from **52%** last year. There is considerable variability within the UK of antenatal detection.

**Fetal anomaly screening** continued nationally despite the pandemic.

# Executive summary

**This report summarises selected findings from the National Congenital Heart Disease Audit (NCHDA), which is a part of the National Cardiac Audit Programme (NCAP).**

It focuses on the activity and trends in the treatment of patients with congenital heart disease (CHD) in the UK and Ireland (not including Scotland which now has its own Scottish Cardiac Audit Programme).

The report covers the financial year 2021/22 and considers the continuing impact of COVID-19 on the care of paediatric and adult CHD patients as we recover from the impact of the pandemic. It compares performance against several quality improvement (QI) metrics derived from national and/or international standards and guidelines.

| Focus of attention | | Audit finding |
|---|---|---|
| **The volume of procedures did not recover fully to pre-pandemic levels, especially for surgical procedures** | → | Overall CHD activity increased by 12% over 2020/21 but the total cases were still 8% down on 2019/20.<br><br>Surgical activity in children saw 3% fewer procedures than in 2020/21 and was 15% lower than 2019/20.<br><br>Catheter-based and EP/pacing procedures were very close to pre-pandemic levels at 98-99%, the figures were higher for adult patients than in children which remained 5-10% lower than in 2019/20. |
| **The rate of antenatal diagnosis fell slightly** | → | Overall, antenatal diagnosis of those requiring a procedure in the first year of life fell to 50.4%, down from 51.9% in 2019/20 (and 52.7% in 2020/21). There is considerable regional variation.<br><br>Antenatal diagnosis was slightly better for Fallot's tetralogy and transposition of the great arteries but slightly lower for hypoplastic left heart syndrome. |
| **Procedural mortality rates for cardiac procedures remains low** | → | Overall, 30-day surgical mortality was 1.6% for both children (those under 16 years of age) and adults, slightly lower than predicted by the risk model. |

# Summary of recommendations

1. Centres should adhere to the new definitions of post-procedure complications which will be released in 2023. All hospitals should comply with the accurate recording of these complications according to the existing definitions.

2. Screening hospitals should aim to increase the rate of antenatal diagnosis of conditions requiring intervention in the first year. This can be supported by congenital heart disease networks reviewing staffing, infrastructure, education and training requirements. There is a need for better linkage with the National Congenital Anomaly and Rare Disease Registration Service to optimise data quality and case ascertainment.

# 1. Introduction

## This report presents key findings from the National Congenital Heart Disease Audit (NCHDA), part of the National Cardiac Audit Programme (NCAP).

It focuses on the activity and trends in the treatment of patients with congenital heart disease (CHD) in the UK and Ireland (not including Scotland which now has its own Scottish Cardiac Audit Programme).

Congenital heart disease (CHD) is a heart condition or defect that develops before a baby is born. It is a chronic, life-long condition with a spectrum of severity from mild to life-threatening. Approximately 1 in 100 births[1] are affected by CHD and it is the main cause of infant mortality. Over 25% 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.[2] Encouragingly, the majority survive to adulthood, and improved survival has led to a rapidly growing population of adults with congenital heart disease (ACHD).[3]

The goal of congenital heart disease services is to make a diagnose as early as possible, ideally before birth, referred to as antenatal diagnosis, and provide excellent continuity of care as patients progress through childhood and into adulthood. Both paediatric and adult patients typically require regular and often lifelong follow-up with specialist CHD professionals and tests of cardiac function are a cornerstone of follow-up.[4 5]

The audit aims to support this by examining service delivery and outcomes for individuals undergoing interventions for paediatric and congenital heart disease. Its dataset is designed by clinicians working in collaboration with the British Congenital Cardiac Association (BCCA) and the Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS).

The report covers the financial year 2021/22. It considers the continuing impact of COVID-19 on the care of paediatric and adult CHD patients as services recover from the impact of the pandemic. During the pandemic, one unit was closed, and patients for that unit were transferred to an adjacent centre. Although we include both single-year and three-year continuous data in the methodology, the impact of these network decisions as well as the pandemic itself on reported activity will be seen in some analyses for a couple more years.

The report compares performance against several quality improvement (QI) metrics derived from national and/or international standards and guidelines. Information on the methodology underpinning the audit, detailed background for all QI metrics and additional data can be found here. Part of the audit data is also available for viewing via the website Understanding Children's Heart Surgery Outcomes, which helps explain survival statistics.

Given the relatively small number of CHD cases annually, combined with the large number of different procedures, composite outcomes are presented to allow meaningful comparison of units and to minimise the risk of identifying individuals. This is in line with the Office for National Statistics (ONS) Confidentiality Guidance for publishing health statistics.

By examining the NCHDA's findings and the report's recommendations, stakeholders can better understand the current state of CHD services and work collaboratively towards improved patient care in the UK and Ireland. Patients, parents, and carers, along with clinicians and commissioners, are encouraged to review the information provided to make informed decisions on treatment options.

**The rest of this report is structured as follows:**

- **Section 2** discusses the ongoing effects of the COVID-19 pandemic on CHD services, including disruptions to care and opportunities for reflection on and learning from long-standing challenges
- **Section 3** focuses on a select few QI metrics derived from national and/or international standards and guidelines, which should remain a priority for hospital teams and those leading service commissioning and development at the Integrated Care System (ICS) level
- Lastly, **Section 4** will provide insights into the future direction of the NCHDA, outlining potential areas of growth and development for the audit.

# 2. Ongoing impact of the COVID-19 pandemic and extent of recovery

Last year's report showed how the COVID-19 pandemic affected all aspects of CHD activity. Both paediatric and ACHD patient volumes fell significantly, with the greatest impact occurring at times of peak COVID-19 admissions when access to hospital care was seriously restricted. Non-procedural activity like outpatient care, inpatient admissions, elective cardiac investigations, planned assessments and access to allied healthcare professionals (psychologists, physiotherapists, dieticians) were equally affected.

This report summarises the continuing impact of the pandemic and the efforts made to restore services during 2021/22.

## 2.1 There was variable recovery of CHD procedural activity

Table 2.1 summarises the change in CHD activity in 2020/21 compared to 2020/21 and before the pandemic in 2019/20. All types of CHD procedure saw increases in numbers other than for children's surgical cases. Case prioritisation and change in case-mix, compounded by several factors mentioned above, could explain the continued drop in children's surgical activity. Catheter based services were not far short of pre-pandemic levels, with an increase in services for ACHD patients combined with a continued shortfall for paediatric services. The rise in number of cases is highly suggestive that the fall seen in the first year of the pandemic was due to logistical constraints and capacity issues rather than a fall in demand.

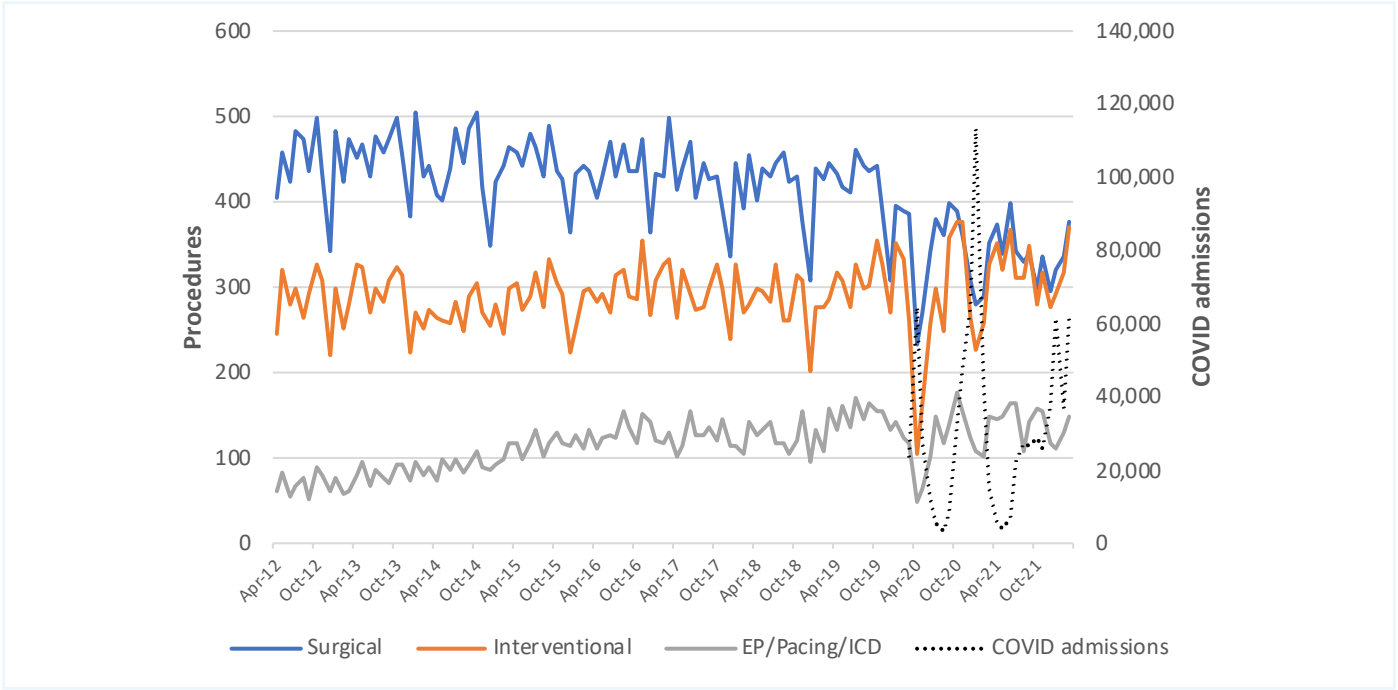
**Table 2.1: CHD procedural activity in 2021/22 compared with 2020/21 and 2019/20 [NCHDA data]**

| Type of CHD procedure | Total procedures | Change from 2020/21I | Change from 2019/20 |
|---|---|---|---|
| Overall procedural activity | 10,889 | +12% | -8% |
| Overall surgical activity | 4,081 | +3% | -15% |
| Surgical activity children | 3,282 | -3% | -14% |
| Surgical activity adults | 799 | +41% | -21% |
| Overall catheter activity | 5,116 | +17% | -1% |
| Catheter activity children | 3,030 | +11% | -5% |
| Catheter activity adults | 2,086 | +26% | +6% |
| Overall EP activity | 1,692 | +19% | - 2% |
| EP activity children | 687 | +14% | -9% |
| EP activity adults | 1,002 | +25% | +4% |

*Note: Data from hospitals in Scotland not included in each year*

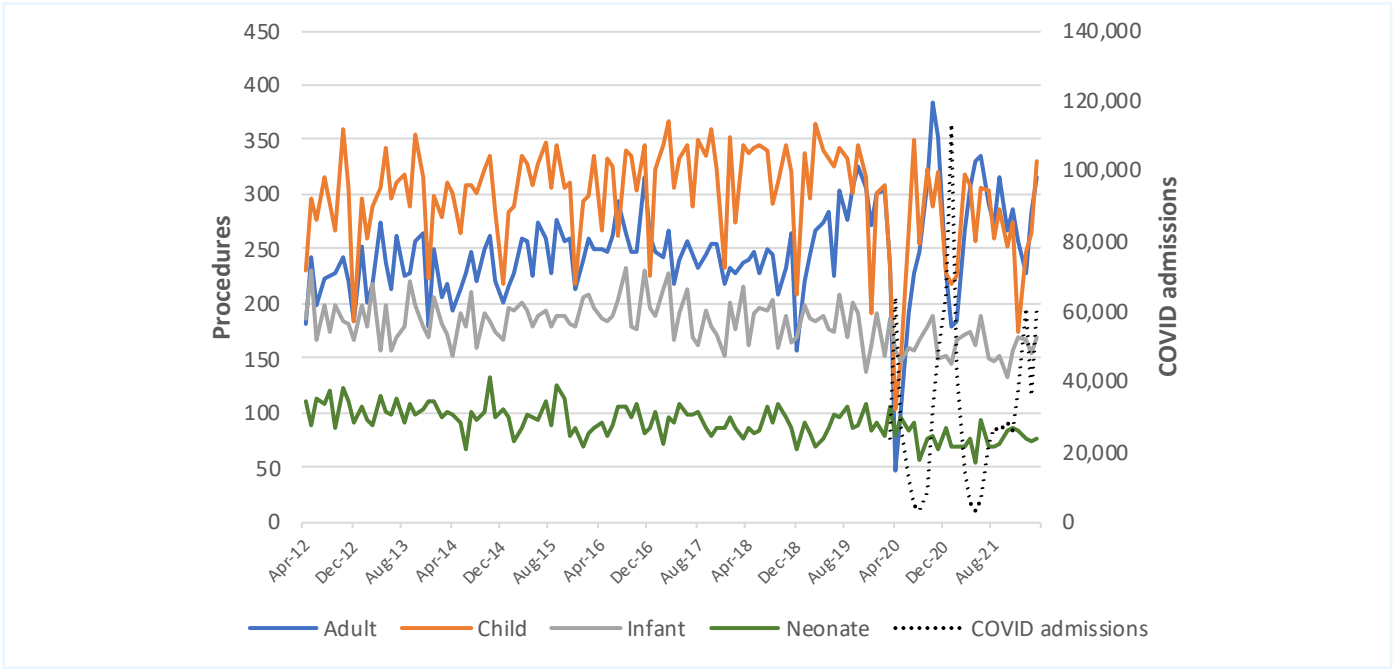
Figure 2.1: illustrates a clear inverse relationship between the number of CHD procedures and peak COVID-19 admissions. The impact was much less after April 2021, although services for adults and children were more impacted by the smaller COVID-19 admission surges than services for infants and neonates [Figure 2.2].

**Figure 2.1: Activity trends for surgical, interventional and EP/pacing/ICD procedures, against UK COVID-19 admissions, 2012/13 - 2021/22 [NCHDA and UKHSA data][6]**




*EP = electrophysiological procedures; ICD = implantable cardioverter defibrillator*

**Figure 2.2: Activity trends by age groups, 2012/13 - 2021/22 [NCHDA and UKHSA data] against UK COVID-19 admissions**



## 2.2 Hospitals are taking action to tackle waiting lists by maximising treatment opportunities

Reduction in elective hospital appointments during the pandemic resulted in substantial increases in waiting times for face-to-face outpatient clinics, both for new and follow-up patients. There were also delays to investigations, including echocardiography, cross-sectional imaging (CT or MRI) and exercise tests. So too, routine assessments and access to allied clinical support, including dentistry, were affected. All these things impacted on the timeliness of elective procedural activity with this subsequently leading to some cases becoming urgent or emergency cases.

Responding to the pandemic forced services to adapt and there could be lessons for potential new ways of working that may provide solutions that ensure timely assessment and case prioritisation in the future. Hospitals have taken several steps to adapt, including:

- expanding clinic hours by additional clinics over weekends and accommodating more patients during sessions
- prioritising appointments using patient triage, based on cardiac diagnosis and the need for review, assisted by virtual consultations
- increasing bed capacity by recruiting more staff and evaluating factors such as short notice staff absenteeism and other unexpected causes limiting bed availability.

## 2.3 Staffing issues are a growing concern

The first year of the pandemic resulted in the widespread redeployment of specialist staff with a negative effect on the delivery of paediatric cardiac and adult CHD services. Further staff shortages have then come from a number of factors, including:

- healthcare workers becoming ill with COVID-19 themselves or experiencing fatigue and mental health issues
- NHS staff retiring early or leaving the profession
- the impact of immigration decisions
- a reduction in new students enrolling in healthcare programmes.[7]

These issues may impact organisations across the country differently (e.g. staffing issues may be of particular concern in regions with higher levels of social deprivation).[8] They will have impacted on medical, nursing and allied health professionals to varying extents. Healthcare organisations may need to consider creative solutions such as increasing staff support, providing well-being and mental health services and focusing on recruitment and retention strategies.

## 2.4 Digital consultations and advanced technology can improve clinical pathways

CHD services can benefit from the use of digital solutions in healthcare which the pandemic has accelerated. Use of digital technology in the post-pandemic period will play a vital role in overall management of CHD patients with better integration and accessibility to patient care:

- Telemedicine reduces some of the geographical barriers to accessing care and improves pre-assessment prior to in-person hospital visits
- Hospitals are steadily transitioning to Electronic Patient Record (EPR) systems. This makes it easier for clinicians and patients to access and capture clinical history, request and input investigations online and provide e-prescriptions.
- Video conferencing is used by staff to communicate, hold work meetings and conferences, and support training, education and research. This includes enabling more participation by referring hospitals and the clinical networks in multidisciplinary team (MDT) meetings.

## 2.5 Building a stronger and well-integrated national CHD Network

As the recovery phase continues, CHD services will need to apply innovative strategies and collaborate with NHS population health management systems to create a sustainable model of change across their services. Local clinical networks have played a vital role in carefully monitoring and ensuring equity of access for all CHD (paediatric and ACHD) patients throughout the pandemic crisis. They have adapted to the changing demography of CHD and the challenges thrown up by the pandemic.

NHS England (NHSE) Specialised Commissioning has worked with local CHD Operating Delivery Networks (ODNs) to understand and quantify bed capacity issues, both on cardiac wards and wards and intensive therapy units (ITUs) This aims to tackle the winter capacity crisis, staffing problems, cancellation of surgical and interventional procedures, and manage the more complex case-mix of all CHD patients requiring longer in-hospital stay and frequent admissions.

Developing a well-integrated national CHD network offers the chance to monitor capacity and performance more robustly, as well as the availability of resources. This would require provision of the necessary underpinning information though clinical and management dashboards shared by national and regional commissioners, clinical leads and network data managers. These would draw on procedural and non-procedural data, including from this audit, to offer a near real-time overview of national CHD activity. It is important that the cardiology networks should work closely with the women and children's networks to ensure a complete picture is obtained.

# 3 Quality Improvement Metrics

## 3.1 Congenital heart disease procedural activity

Almost 11,000 procedures in children and adults were submitted to the audit in 2021/22. 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. 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.[9] [10]

### 3.1.1 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 with the aim 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[9] require that:<br>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, see footnotes to Figures 3.1 and 3.2), per year (average over 3 years).<br><br>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.<br><br>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.<br><br>Congenital Heart Disease Services: Decision Making Business Case November 2017: main document.[11]<br><br>Congenital Heart Disease Services: Decision Making Business Case November 2017: Annex B, page 358 (Appendix 1, Annex 6).[11] |

| QI Metric Description/Name | Procedural activity by age group and each centre Catheter-based and surgical activity |
|---|---|
| **Numerator** | NHSE countable surgical procedures - for neonate, child and adults. |
| **Denominator** | NHSE countable surgical procedures. |
| **Trend** | Overall activity increased by 12% when compared to 2020/21. Total surgical activity showed a marginal increase, as ACHD surgery made a good recovery (increasing by 43%) but paediatric congenital heart surgery dropped by 3% [Table 3.1, Table 3.2, Figure 3.1, Figure 3.2 and Figure 3.3]. |
| **Variance** | Figure 3.1 and Figure 3.2 show the impact on all types of procedures through the course of the pandemic.<br><br>In Figure 3.3, the data are split by age groups, with the reduction in procedural activity significantly affecting children and adult groups, while neonates and infants were less impacted. |

### 3.1.2 Audit results: all Paediatric and CHD centres

**Table 3.1: All CHD procedure volumes by age group, UK and the Republic of Ireland (not including Scotland), 2021/22 [NCHDA data]**

| | Procedures (all ages) | Procedures (under 16 years) | Procedures (≥16 years) |
|---|---|---|---|
| **Overall activity** | 10,889 | 7,002 | 3,022 |
| **Surgical procedure activity** | | | |
| Surgery undertaken using cardiopulmonary bypass | 3,187 | 2,473 | 714 |
| Surgery undertaken without using cardiopulmonary bypass (including surgical EP) | 732 | 661 | 71 |
| Hybrid procedures | 65 | 55 | 10 |
| Primary ECMO | 8* | 83 | <3 |
| Ventricular Assist Device (VAD) | 1* | 10 | <3 |
| **Total** | **4,081** | **3,282** | **799** |

| | Procedures (all ages) | Procedures (under 16 years) | Procedures (≥16 years) |
|---|---|---|---|
| **Catheter procedure activity** | | | |
| Interventional catheterisation procedures | 3,783 | 2,148 | 1,635 |
| Diagnostic catheter procedures | 1,333 | 857 | 451 |
| **Total** | **5,116** | **3,030** | **2,086** |
| **Electrophysiological activity (non-surgical)** | | | |
| Implantable Cardioverter Defibrillator (ICD) | 167 | 57 | 110 |
| Pacemaker procedures | 442 | 129 | 313 |
| EP ablation and EP diagnostic procedures | 1083 | 504 | 579 |
| **Total** | **1,692** | **687** | **1,002** |

**Note:** *Activity numbers are those procedures agreed by NHS England to be 'countable' towards individual operator activity. In the 2021/22 audit, data in Scottish centres were not included 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. Only primary cardiac ECMO procedures are countable, when this procedure is undertaken in isolation and not as a support operation after another congenital heart procedure (in which circumstances, these are considered as 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. * is a digit between 0 and 9, i.e. 8* is a number between 80 and 89. The full hospital names can be found in Annex A.*

**Table 3.2: Procedure volumes, UK and the Republic of Ireland (not including Scotland) 2012/13 - 2021/22 [NCHDA data]**

| Year | Surgical | Hybrid | Interventional catheter & EP procedures | | | Diagnostic catheter | Total |
|---|---|---|---|---|---|---|---|
| | | | | | | | |
| 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 |
| 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 |
| **Total** | **52,653** | **590** | **12,821** | **1,297** | **36,210** | **11,061** | **114,632** |

**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.*

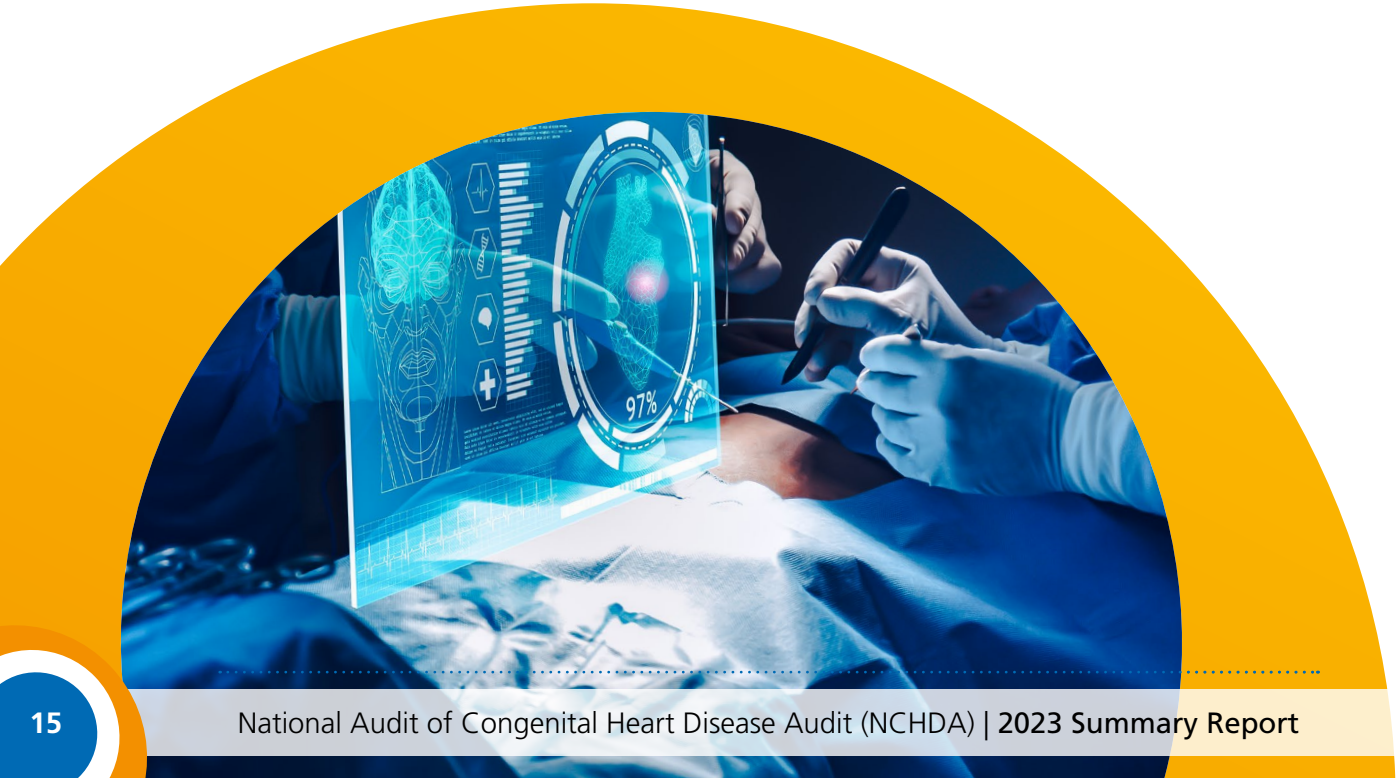
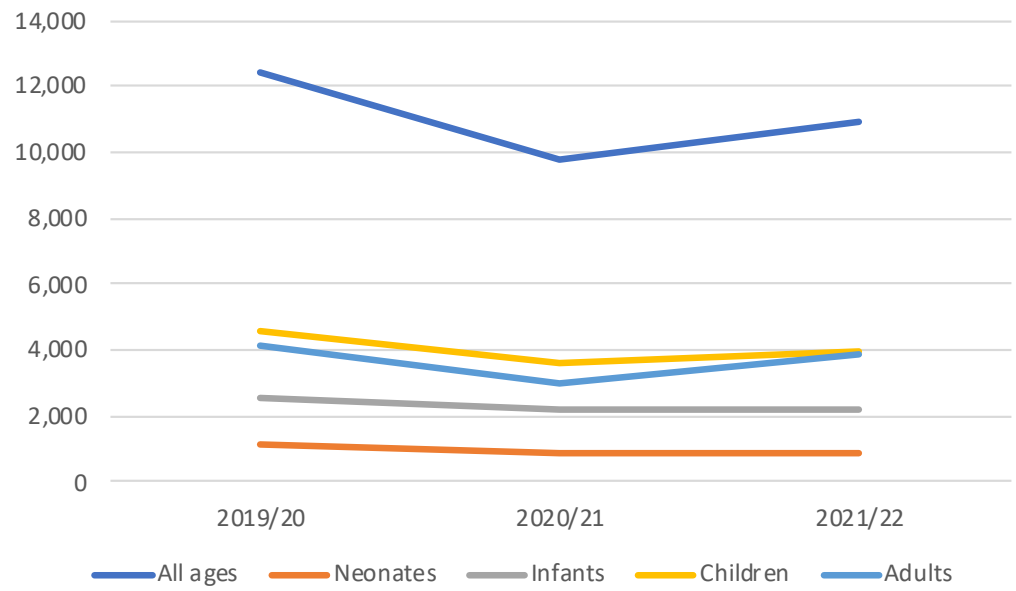


**Figure 3.1: Number of procedures by age group, UK and the Republic of Ireland (not including Scotland), 2019/20 - 2021/22 [NCHDA data]**




*A full breakdown of 30-day outcomes by age group for all procedures (2019/20 to 2021/22) as well as a breakdown of activity for centres undertaking major congenital cardiac procedures (2019/22) for children and adults in the UK can be found here.*

**Figure 3.2: Surgical, interventional catheter-based and electrophysiological procedures by quarter, UK and the Republic of Ireland (not including Scotland), 2012/13 - 2021/22 [NCHDA data]**

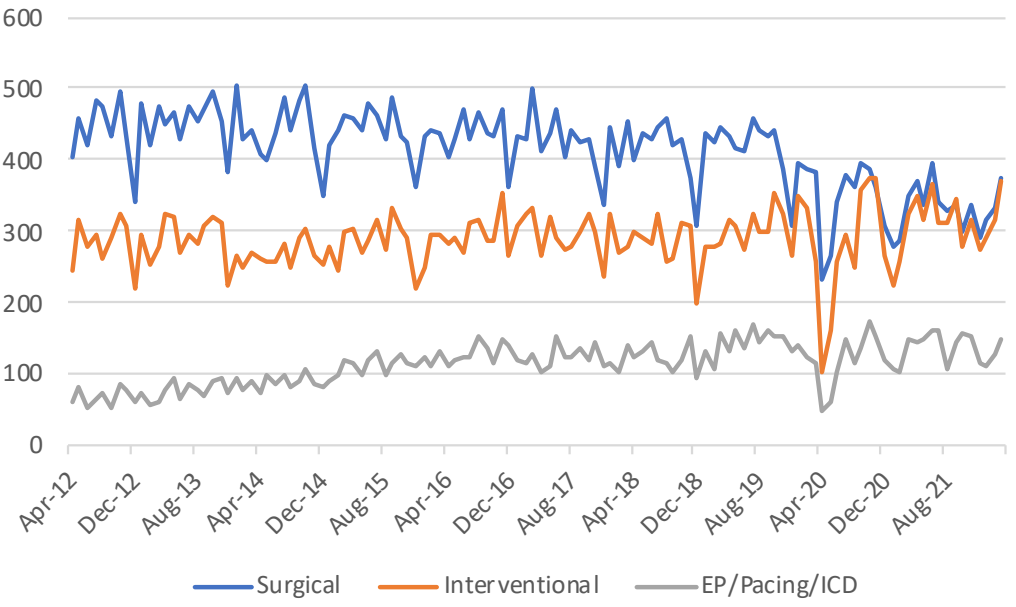
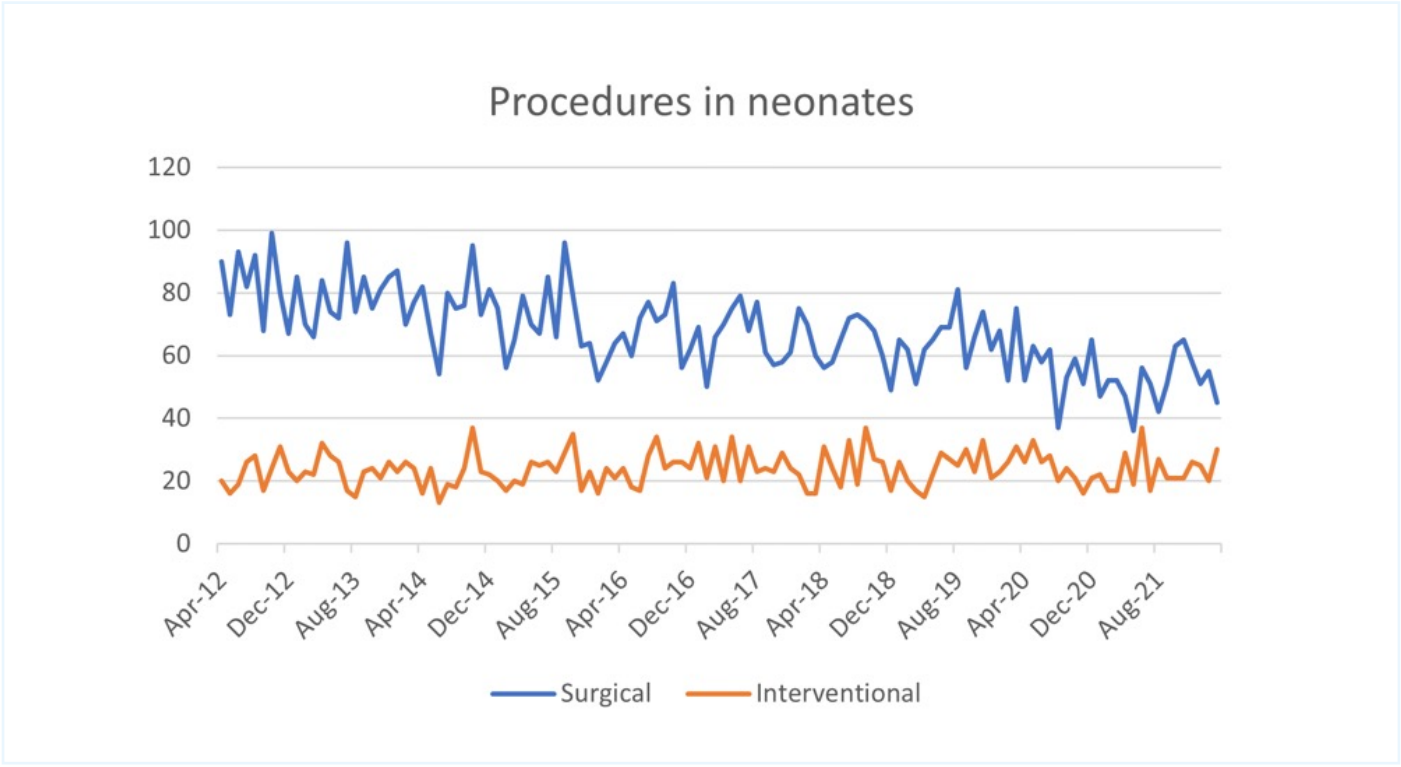
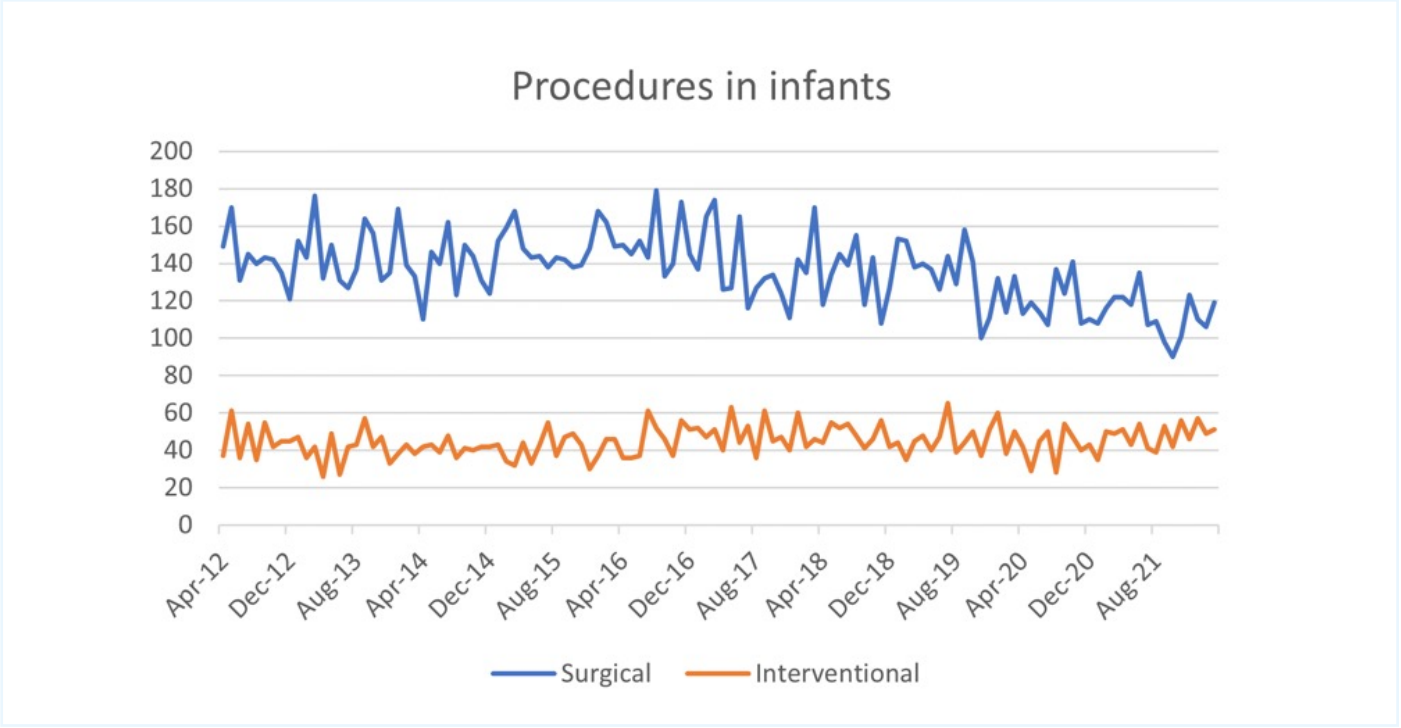
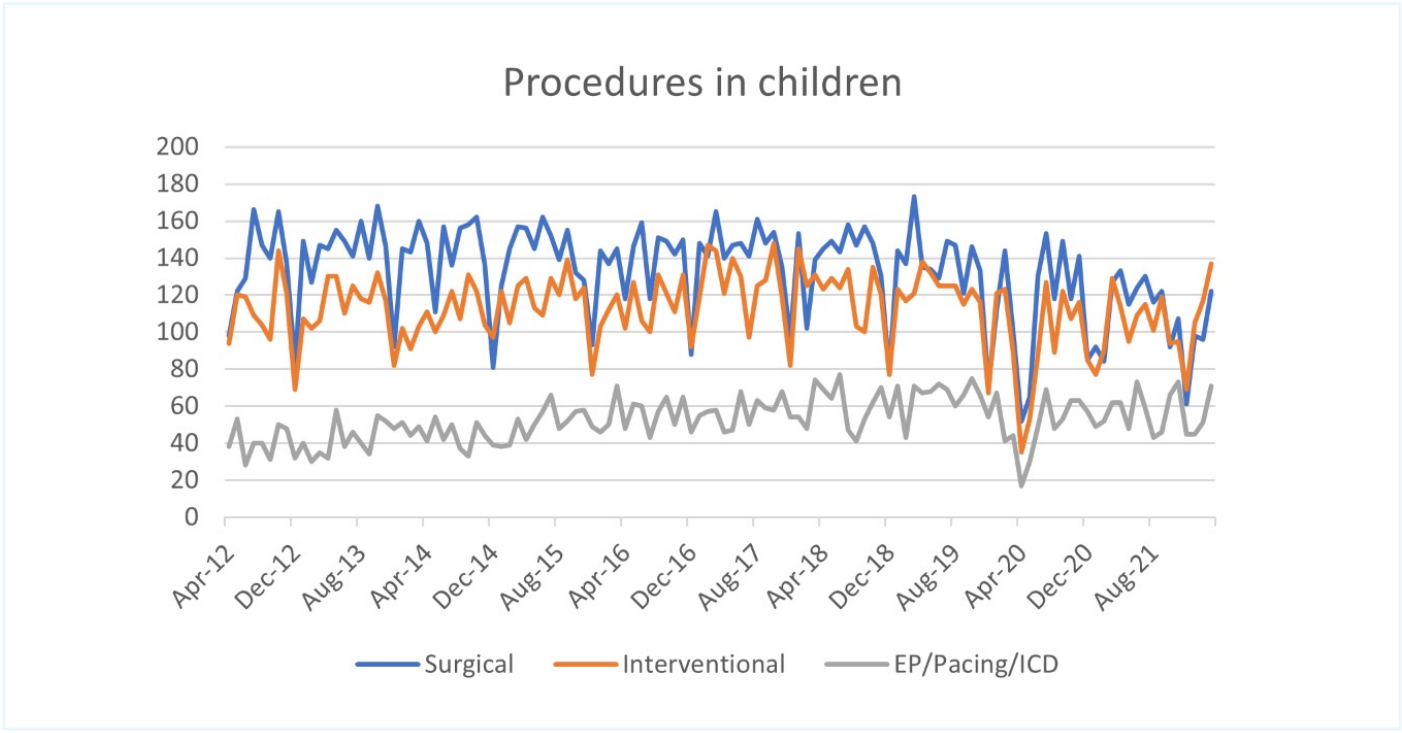
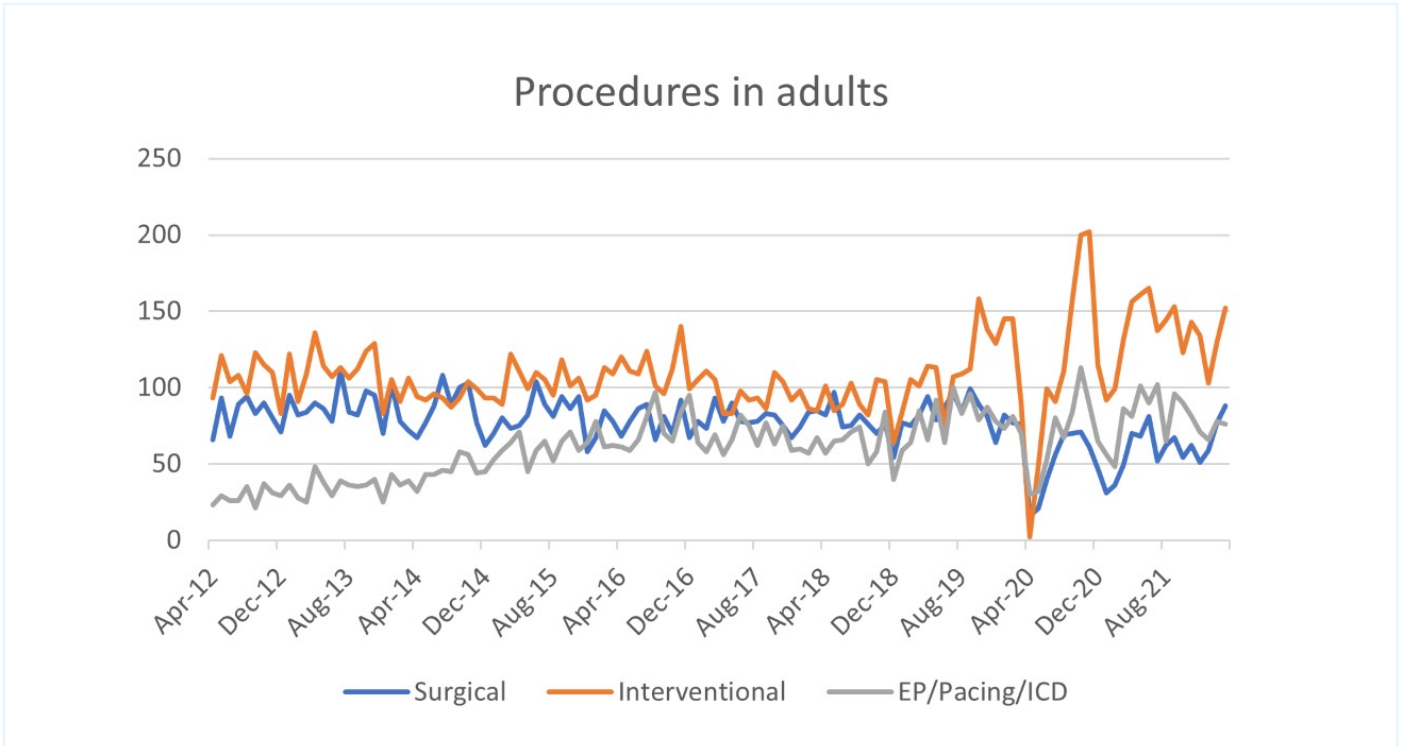


**Figure 3.3: Surgical, interventional catheter-based and electrophysiological procedures by age group, UK and the Republic of Ireland (not including Scotland), 2012/13 - 2021/22 [NCHDA data]**






## 3.2 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[12 13]
- Society of Thoracic Surgeons - European Association for Cardio-thoracic Surgery (STAT) mortality score for adults (16 years and over) [14]

### 3.2.1 Overview of QI metric: Summary of 30-day Mortality pertaining to aggregated and specific procedure outcomes, 2019/22

| 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.<br><br>Exemplary centre level performance can be used as a benchmark for quality improvement initiatives at underperforming centres. |
| **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.<br>• 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.<br>• 30-day mortality at centre and procedure levels for 83 specific CHD procedures (51 surgical, 22 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[12]<br>• Improving risk adjustment in the PRAiS model for mortality after paediatric cardiac surgery and improving public understanding of its use in monitoring outcomes[13]<br>• 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[14] |
| **Numerator** | Number of patients whose death is recorded by centre or ONS linkage. |
| **Denominator** | Total expected risk-adjusted mortality. |
| **Trends**<br><br>**Variance** | Overall non-risk-adjusted 30-day mortality remains low at 1.6%. Risk-adjusted survival was much better [Figure 3.4] and [Figure 3.5].<br><br>The 30-day mortality outcomes following the 83 specific procedures or for aggregated surgery in children or adults with CHD are available on the NICOR website. |

### 3.2.2 **Audit results: 30-day survival after surgery in children**

Table 3.3 shows a total of 9,586 paediatric patients operated upon during 2019/22. The PRAiS model showed that the overall survival (98.3%) was slightly higher than the risk predicted survival (97.9%). To help understand the relative complexity of cases at each centre, the average PRAiS2 risk-adjusted mortality per patient operated upon at each of the 11 centres is reported in the final column. This shows significant variance between centres (from 1.32% to 2.40%), highlighting different risk profiles of complex CHD and case-mix undertaken by individual centres.

The overall actual to predicted survival ratio was 1.003.

**Table 3.3: Actual and predicted survival, using PRAiS2 risk adjustment methodology (average predicted risk per case), for all 11 centres undertaking procedures in patients under 16 years of age, April 2019 - March 2022 [NCHDA data]**

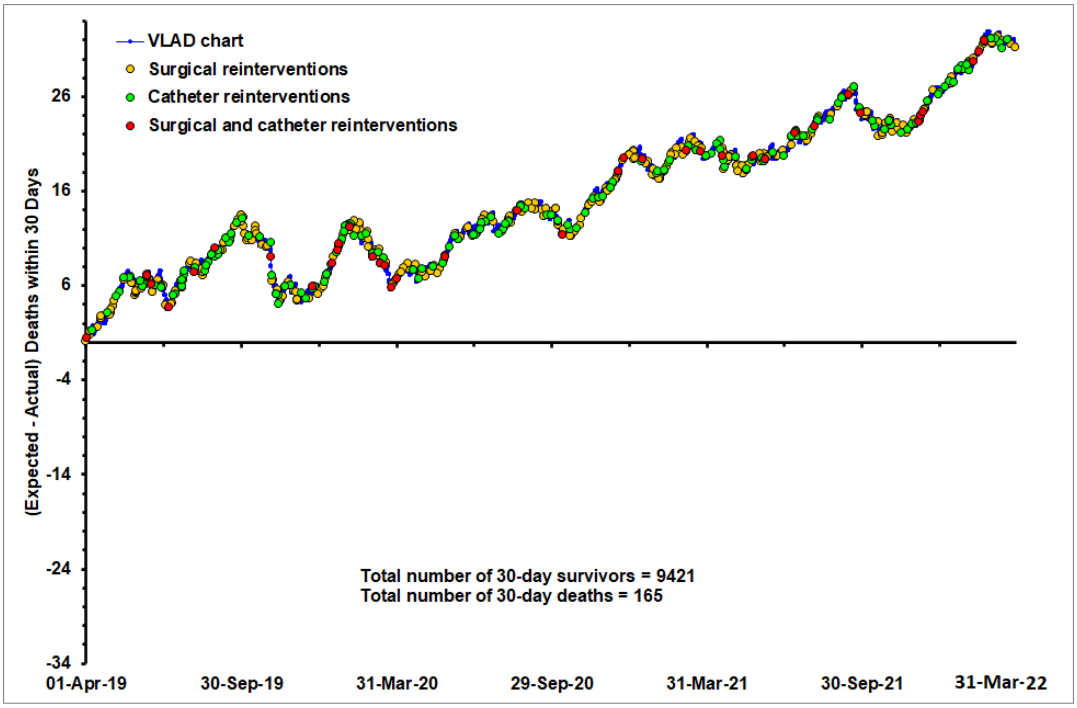
| Hospital | Surgical episodes | Survivors | Deaths | Actual survival | Predicted survival | Actual/ predicted | Average risk per case |
|---|---|---|---|---|---|---|---|
| FRE | 511 | 497 | 14 | 97.3% | 97.7% | 0.995 | 2.30% |
| GRL | 578 | 572 | 6 | 99.0% | 98.0% | 1.01 | 2.04% |
| BRC | 710 | 697 | 13 | 98.2% | 97.8% | 1.003 | 2.16% |
| SGH | 720 | 708 | 12 | 98.3% | 97.6% | 1.007 | 2.37% |
| OLS | 963 | 935 | 28 | 97.1% | 98.3% | 0.988 | 1.71% |
| ACH | 974 | 955 | 19 | 98.1% | 97.7% | 1.003 | 2.29% |
| LGI | 920 | 904 | 16 | 98.3% | 97.8% | 1.005 | 2.23% |
| NHB | 661 | 653 | 8 | 98.8% | 98.7% | 1.001 | 1.32% |
| GUY | 932 | 913 | 19 | 98.0% | 97.8% | 1.001 | 2.17% |
| BCH | 1,141 | 1,118 | 23 | 98.0% | 97.6% | 1.004 | 2.40% |
| GOS | 1,476 | 1,469 | 7 | 99.5% | 98.3% | 1.013 | 1.71% |
| **Overall** | **9,586** | **9,421** | **165** | **98.3%** | **97.9%** | **1.003** | **2.1%** |

*The full hospital names can be found in Annex A*

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 VLAD chart line in Figure 3.4 shows the national outcomes between 1st April 2019 and 31st March 2022. There is a continuing upward trend over 2021/22 suggesting that actual results were outperforming those expected, despite the pandemic. Although total paediatric surgical activity for the last 12 months has not completely recovered to pre-pandemic levels, it is unlikely that this has had an impact on these risk-adjusted results.

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.[12] A further recalibration of the PRAiS model is ongoing.

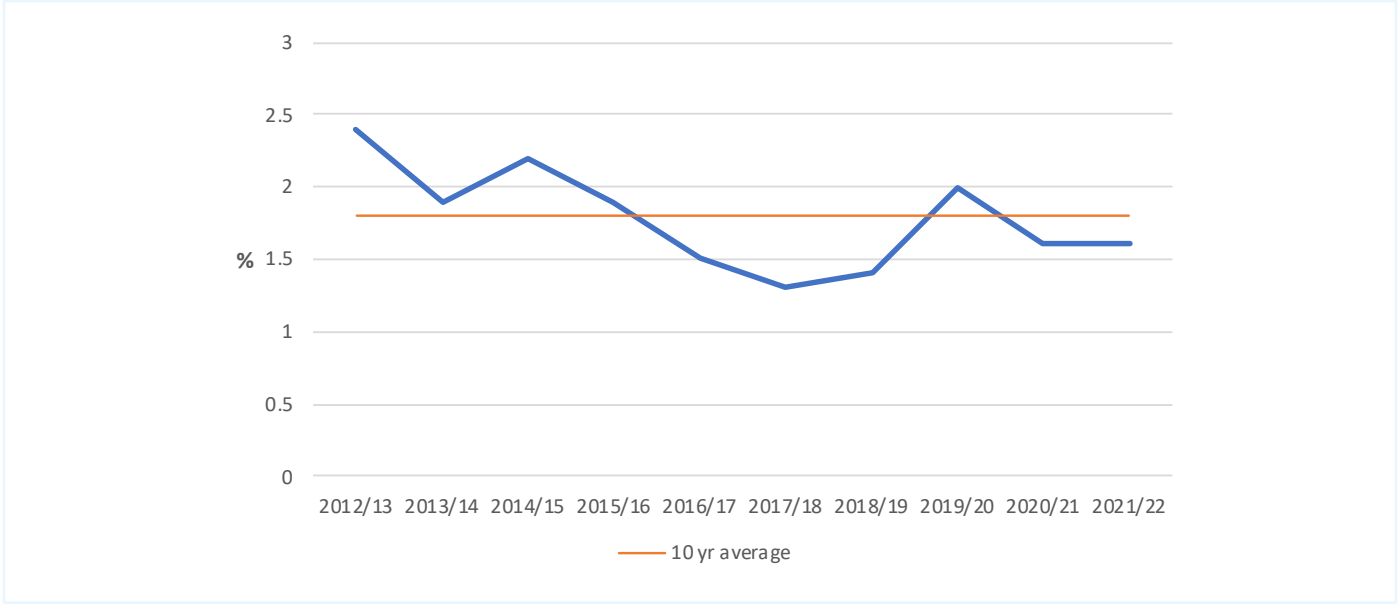
**Figure 3.4: Variable Life Adjusted Display (VLAD) chart for all 11 paediatric centres in the UK and Republic of Ireland (not including Scotland) undertaking procedures in patients under 16 years of age, April 2019 - March 2022 [NCHDA data]**




The crude unadjusted mortality for surgical procedures in children over the last 10 years is shown in Figure 3.5. The crude mortality rate for 3,282 surgical procedures undertaken in children under 16 years of age was 1.6%. This is lower than the 10-year average crude mortality rate of 1.8% and unchanged from the rate during the pandemic.

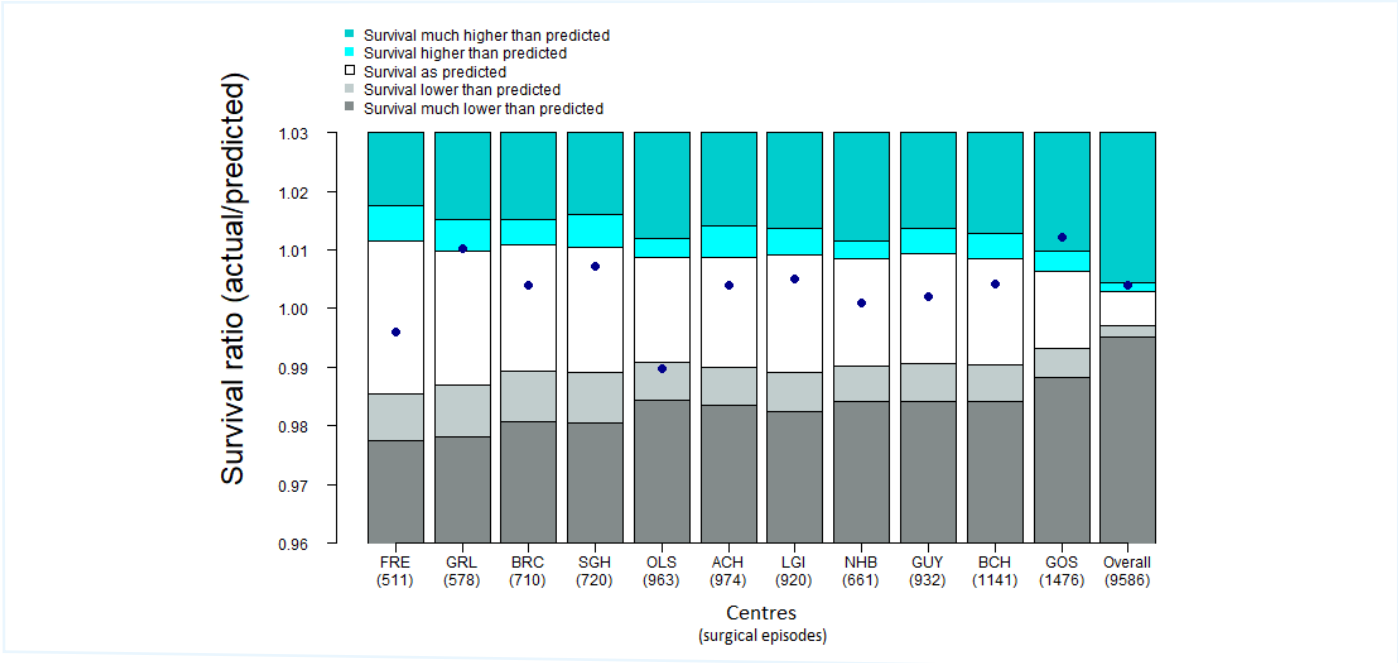
Although the decrease in mortality during and after the pandemic may result from a reduction in total number of operations, a different case-mix and/or complexity of CHD, the VLAD chart above indicates that actual performance has been better than predicted and the pandemic seems to have had little effect.

**Figure 3.5: Unadjusted 30-day mortality in children under 16 years after surgery, UK and the Republic of Ireland (not including Scotland), 2012/13 - 2021/22 [NCHDA data]**




The risk-adjusted 3-year results for each centre are shown in Figure 3.6. Over the last three years, all but one centre had survival rates that were equal to or better than predicted (a description of the methodology, including the link to alert and alarm control limits for aggregated outcomes after all surgical procedures in children, can be found here).

**Figure 3.6: Actual versus predicted survival for all 11 centres undertaking cardiac procedures in patients under 16 years of age in the UK and Republic of Ireland (not including Scotland), using PRAiS2 risk adjustment methodology, April 2019 - March 2022 [NCHDA data]**




*Note: Outcomes are adjusted for age, weight, diagnosis, comorbidities and procedures performed. The full hospital names can be found in Annex A. Our Lady's Children's Hospital, Dublin (OLS) is just into the negative Alert level band. After external review of OLS results (including correction and verification of appropriate coding), the NCHDA Domain Expert Group was satisfied that results were predominantly affected by the first two years of the three-year analysis, results for 2021/22 were not a cause for concern and results from earlier years were related to individual complex cases.*

### 3.2.3 Audit results: 30-day survival after adult congenital heart surgery

Eleven centres each undertook more than 30 adult surgical procedures between 2019/20 to 2021/22 for a total of 2,120 patients [Table 3.4]. All the hospitals achieved 30-day survival as predicted (the actual to predicted survival ratio was 1.002).

The audit also calculates the average risk-adjusted mortality per patient operated upon at each of the 11 centres, which varied between 1.47% to 2.45%. This demonstrates the very different case-mix undertaken by individual hospitals (e.g. Newcastle is known to undertake cardiac transplantation in some patients with a background of complex congenital heart disease).

Approximately 9% fewer deaths resulted than was than predicted by the STAT mortality model [Figure 3.7]. In addition, none of the hospitals were outliers on any of the 44 specific surgical procedures analysed for 30-day mortality (i.e. their outcomes were not outside the statistically acceptable limits of the STAT risk-adjustment model).

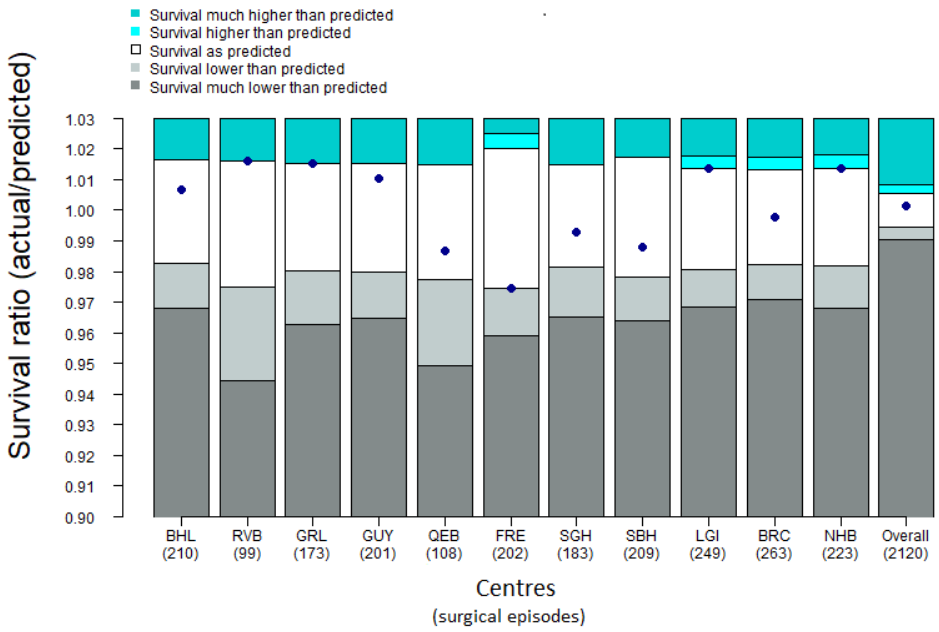
**Table 3.4: Actual and predicted survival using STAT mortality risk methodology of average predicted risk of death per case, for 11 centres undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over, April 2019 - March 2022 [NCHDA data]**

| Hospital | Surgical episodes | Survivors | Deaths | Actual survival | Predicted survival | Actual/ predicted | Average risk per case |
|---|---|---|---|---|---|---|---|
| BHL | 210 | 208 | <3 | 99% | 98.4% | 1.00* | 1.62% |
| RVB | 99 | 99 | 0 | 100.0% | 98.4% | 1.0162 | 1.59% |
| GRL | 173 | 173 | 0 | 100.0% | 98.5% | 1.0154 | 1.52% |
| GUY | 201 | 200 | <3 | 99% | 98.5% | 1.01* | 1.51% |
| QEB | 108 | 105 | 3 | 97.2% | 98.5% | 0.9867 | 1.47% |
| FRE | 202 | 192 | 10 | 95.1% | 97.6% | 0.9744 | 2.45% |
| SGH | 183 | 179 | 4 | 97.8% | 98.5% | 0.9927 | 1.47% |
| SBH | 209 | 203 | 6 | 97.1% | 98.3% | 0.9881 | 1.70% |
| LGI | 249 | 248 | <3 | 99% | 98.3% | 1.01* | 1.73% |
| BRC | 263 | 258 | 5 | 98.1% | 98.3% | 0.9978 | 1.68% |
| NHB | 223 | 222 | <3 | 99% | 98.2% | 1.01* | 1.79% |
| **Overall** | **2120** | **2,087** | **33** | **98.4%** | **98.3%** | **1.0015** | **1.71%** |

*N.B. 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 full hospital names can be found in Annex A.*

** is a number between 0 and 9.*

**Figure 3.7: Actual and predicted survival rates using STAT mortality score methodology for the 11 centres in the UK undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over, April 2019 - March 2022 [NCHDA data]**




**Note:** *The last bar is overall survival rates for all centres undertaking patients 16 years and over. 'Lung transplant' procedures have been excluded in the analysis. Only centres with more than 30 adult surgical procedures were included. Scottish centres not included.*

## 3.2.4 Audit results: 30-day survival after 83 specific procedures

Survival at thirty 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. 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, which sets out a process for providing assurance that all hospitals provide the expected quality of care.[15] For details, click here.

## 3.3 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.[16]

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.

Post-procedure complication rates for children (less than 16 years of age) following 3282 surgical procedures, 3030 transcatheter interventions and 687 electrophysiology procedures at 11 UK and Republic of Ireland centres during 2018/21 are reported and can be reviewed here.

### 3.3.1 Overview of QI metric: Summary of post-procedural complications

| QI Metric Description/ Name | Incidence of six post-procedural complications: |
|---|---|
| | • Use of extracorporeal life support<br>• Need for renal replacement therapy (including peritoneal dialysis)<br>• Unplanned need for a pacemaker<br>• Prolonged pleural drainage<br>• Need for emergency procedure following catheter intervention<br>• 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 complications continue 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[16]<br>• 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[17]<br>• 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[18] |
| **Numerator** | Count of patients with a coded complication. |
| **Denominator** | Countable surgical procedures. |
| **Trend** | This report has analysed 3-year aggregate data for individual hospitals providing a better understanding of complication rates in line with the case mix and complexity of procedures in different centres. |
| **Variance** | While some inter-centre variance is seen in the incidence of each complication (Table 3.5), difference in case management between centres could be an important factor.<br><br>Detailed case-mix and specific procedure adjusted analysis of causation is required in the future to establish best practice for benchmarking. |

### 3.3.2 **Audit results**

Table 3.5 demonstrates the rate of four surgical-related and two interventional catheter-related complications across 11 paediatric centres for the period between 2019 and 2022.

**Table 3.5: Rate of six post-procedural complications for 11 paediatric centres in the UK and Republic of Ireland (not including Scotland), April 2019 - March 2022 [NCHDA data]**

| Hospital | ECMO (%) | Renal support (%) | Unplanned pacemaker (%) | Prolonged pleural drainage (%) | Transcatheter complication requiring an urgent procedure (%) | Catheter device embolisation (%) |
|---|---|---|---|---|---|---|
| BCH | 2.36 | 1.66 | 1.2 | 5.81 | 0.73 | 0.89 |
| BRC | 1.8 | 7.86 | 2.79 | 3.84 | 0.82 | 0.14 |
| OLS | 2.02 | 1.06 | 1.67 | 4.15 | 0.72 | 0.61 |
| LGI | 1.21 | 3.36 | 0.84 | 0.84 | 0.71 | 0.89 |
| GRL | 3.85 | 0.96 | 0.62 | 0.48 | 0.27 | 0.55 |
| ACH | 3.63 | 4.64 | 1.33 | 2.71 | 1.08 | 0.78 |
| GUY | 1.4 | 5.02 | 0.5 | 2.04 | 0.89 | 0.65 |
| GOS | 1.92 | 3.53 | 0.72 | 3.53 | 0.42 | 0.24 |
| NHB | 2.2 | 2.74 | 1.07 | 2.5 | 0.79 | 1.19 |
| FRE | 4.9 | 4.27 | 1.48 | 0.85 | 0.52 | 0.83 |
| SGH | 1.21 | 2.19 | 1.56 | 4.04 | 0.55 | 0.47 |
| **Total** | **2.29** | **3.38** | **1.2** | **3.02** | **0.71** | **0.68** |

*ECMO = Extracorporeal Membranous Oxygenation.*

There is variation between centres. 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 is completing a review of the definitions of all complications, to be released in 2023, and will include an education programme for all participating centres to ensure that data are collected consistently. This will enable a further interpretation of warranted or unwarranted variation.

### 3.3.3 **Recommendation**

Centres should adhere to the new definitions of post-procedure complications which will be released in 2023.

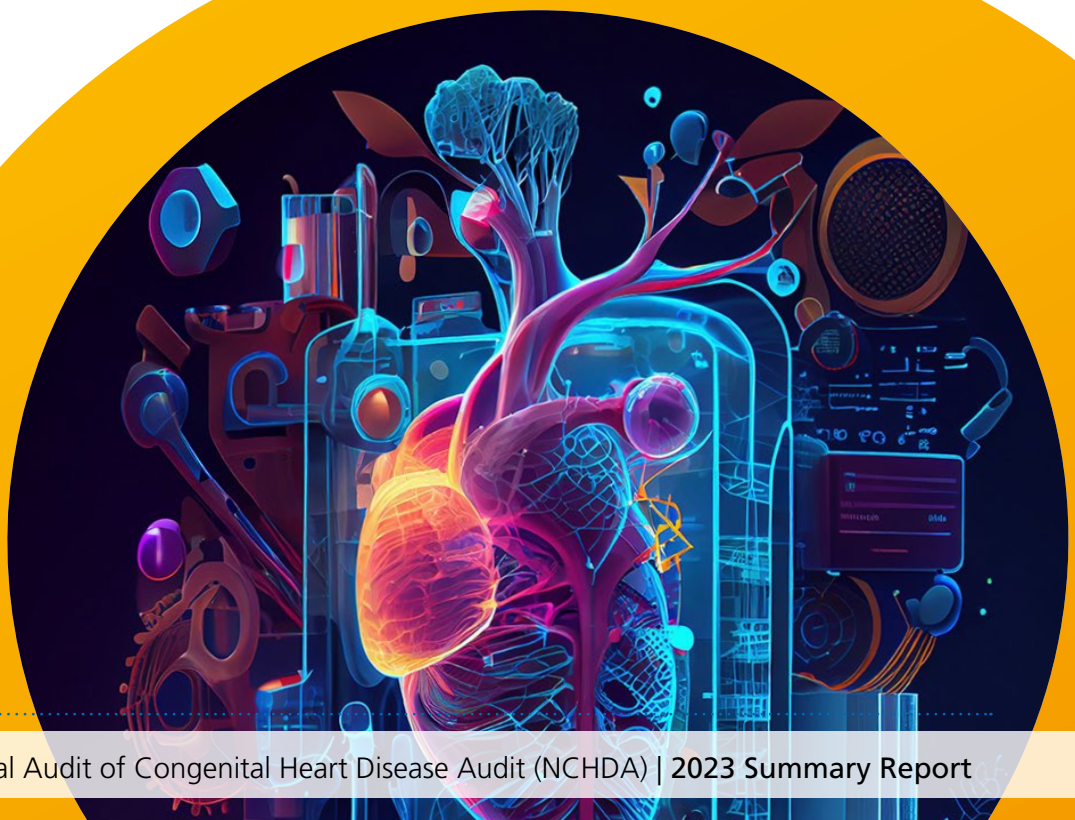
All hospitals should comply with the accurate recording of these complications according to the existing definitions.

## 3.4 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.[19 20] 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.[21] Poor antenatal diagnosis rates also limits the opportunity to counsel expectant patients.[22]

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.[23]



### 3.4.1 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)<br>• Transposition of the great arteries with intact ventricular septum (TGA-IVS)<br>• Tetralogy of Fallot (TOF)<br>• 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:<br>• Achieve diagnosis PPD rate of at least 75% for all abnormalities where an intervention is undertaken in the first year of life;<br>• 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.[21]<br>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.[22] |
| **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. |

| QI Metric Description/Name | Antenatal diagnosis of CHD in those requiring a procedure in infancy - overall and 4 specific diagnoses: |
|---|---|
| **Trend** | This year we have used Regional Integrated Care System (ICS) to map PPD rates for UK and Republic of Ireland (Scottish centres not included).[23] There is a slight drop in overall detection when compared to 2020/21 as shown in Table 3.6. It is important to note that prenatal screening continued throughout the pandemic. |
| **Variance** | Figure 3.9: While considerable regional variation remains between centres, no centre achieves such a low diagnostic rate that would make them a negative outlier. |

### 3.4.2 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 50.4% for all infants requiring a procedure in the first year of life [Table 3.6 and Figure 3.8] slightly lower compared to 2020/21. 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.

Figure 3.9 demonstrates the national variation of antenatal diagnosis rates in 2020/21 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).

**Table 3.6: Antenatal diagnosis in the UK and Republic of Ireland (not including Scotland), 2012/13 - 2021/22[NCHDA data]**

| Year | Number of cases with antenatal diagnosis | Rate of antenatally diagnosis |
|---|---|---|
| 2012/13 | 723 | 33.6% |
| 2013/14 | 804 | 38.2% |
| 2014/15 | 814 | 39.8% |
| 2015/16 | 863 | 41.8% |
| 2016/17 | 908 | 42.9% |
| 2017/18 | 1123 | 51.9% |
| 2018/19 | 1099 | 51.4% |
| 2019/20 | 1088 | 51.9% |
| 2020/21 | 902 | 52.7% |
| 2021/22 | 844 | 50.4% |

*Note: Activity reduction compared to previous years' results from exclusion of Scotland data*

**Figure 3.8: Antenatal diagnosis in the UK and Republic of Ireland (not including Scotland), 2012/13 - 2021/22 [NCHDA data]**

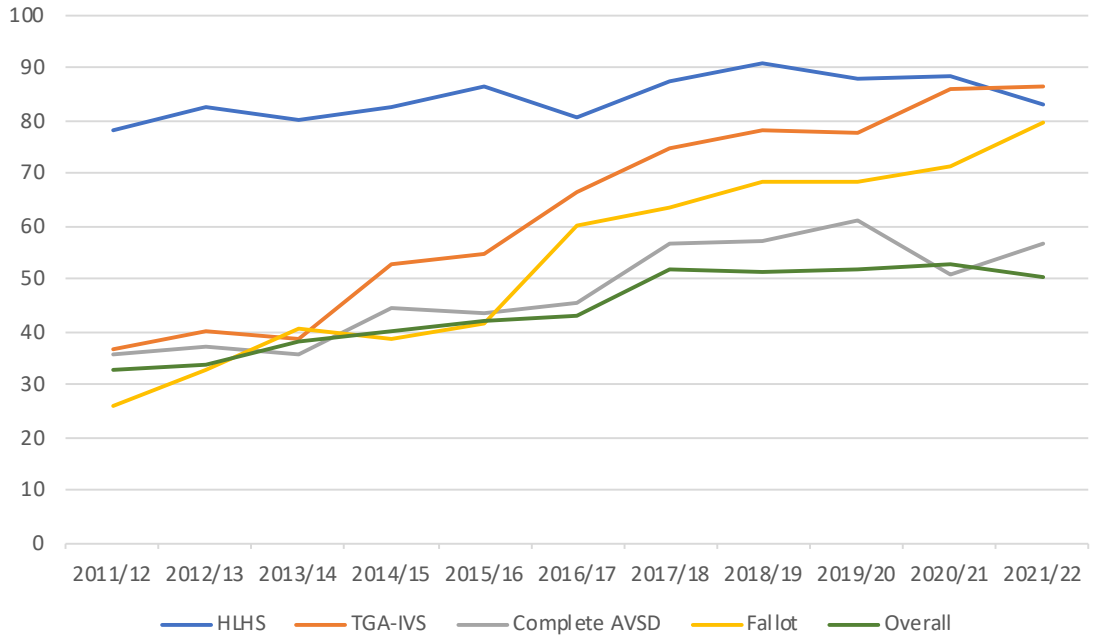



**Table 3.8: Antenatal diagnosis in the UK and Republic of Ireland (not including Scotland) by ICS, 2021/22 [NCHDA data]**

| ICS | Number of cases with antenatal diagnosis | Rate of antenatally diagnosis |
|---|---|---|
| Channel Islands | 3 | 60% |
| England | 686 | 49% |
| Isle of Man | 0 | 0% |
| Northern Ireland | 18 | 54% |
| Republic of Ireland | 99 | 55% |
| Wales | 38 | 56% |
| Healthier Lancashire and South Cumbria | 16 | 43% |
| South Yorkshire and Bassetlaw | 15 | 37% |
| Herefordshire and Worcestershire | 10 | 43% |
| Mid and South Essex | 13 | 68% |
| Bedfordshire, Luton and Milton Keynes | 10 | 42% |
| Birmingham and Solihull | 23 | 53% |
| Cumbria and North East | 32 | 39% |
| Joined Up Care Derbyshire | 13 | 48% |
| Channel Islands | 3 | 60% |
| Suffolk and North East Essex | 7 | 35.% |
| Devon | 11 | 50% |
| Lincolnshire | 6 | 37% |
| Leicester, Leicestershire and Rutland | 12 | 41.% |
| Our Healthier South East London | 25 | 66% |
| Kent and Medway | 26 | 54% |
| Hertfordshire and West Essex | 19 | 49% |
| East London Health and Care Partnership | 37 | 49% |
| North London Partners in Health and Care | 16 | 48% |
| Norfolk and Waveney Health and Care Partnership | 10 | 53% |

| ICS | Number of cases with antenatal diagnosis | Rate of antenatally diagnosis |
|---|---|---|
| Staffordshire and Stoke on Trent | 16 | 70% |
| Frimley Health and Care ICS | 9 | 41% |
| Sussex and East Surrey Health and Care Partnership | 21 | 52% |
| Shropshire and Telford and Wrekin | 0 | 0% |
| Greater Manchester Health and Social Care Partnership | 32 | 48% |
| Humber, Coast and Vale | 16 | 47% |
| Bath and North East Somerset, Swindon and Wiltshire | 13 | 65% |
| Northamptonshire | 10 | 50% |
| Gloucestershire | 5 | 42% |
| Hampshire and the Isle of Wight | 19 | 43% |
| North West London Health and Care Partnership | 42 | 61% |
| Somerset | 16 | 73% |
| Nottingham and Nottinghamshire Health and Care | 10 | 38% |
| Cornwall and the Isles of Scilly Health and Social Care Partnership | 4 | 36% |
| Buckinghamshire, Oxfordshire and Berkshire West | 21 | 46% |
| The Black Country and West Birmingham | 23 | 62% |
| Cambridgeshire and Peterborough | 18 | 50% |
| Bristol, North Somerset and South Gloucestershire | 12 | 54% |
| Dorset | 6 | 46% |
| South West London Health and Care Partnership | 16 | 59% |
| West Yorkshire and Harrogate (Health and Care Partnership) | 33 | 49.3% |

| ICS | Number of cases with antenatal diagnosis | Rate of antenatally diagnosis |
|---|---|---|
| Coventry and Warwickshire | 13 | 68.4% |
| Surrey Heartlands Health and Care Partnership | 10 | 47.6% |
| Cheshire and Merseyside | 20 | 42.6% |
| North Wales | 12 | 36.4% |
| South Wales | 26 | 55.3% |
| 7A2 | 3 | 50.0% |
| 7A3 | 5 | 62.5% |
| 7A4 | 4 | 80.0% |
| 7A5 | 6 | 54.5% |
| 7A6 | 5 | 38.5% |
| 7A7 | 3 | 75.0% |
| **Total** | **844** | **50.4%** |

Figure 3.9 and Figure 3.10 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 the data relate only to continuing pregnancies where babies born have required an intervention in infancy.

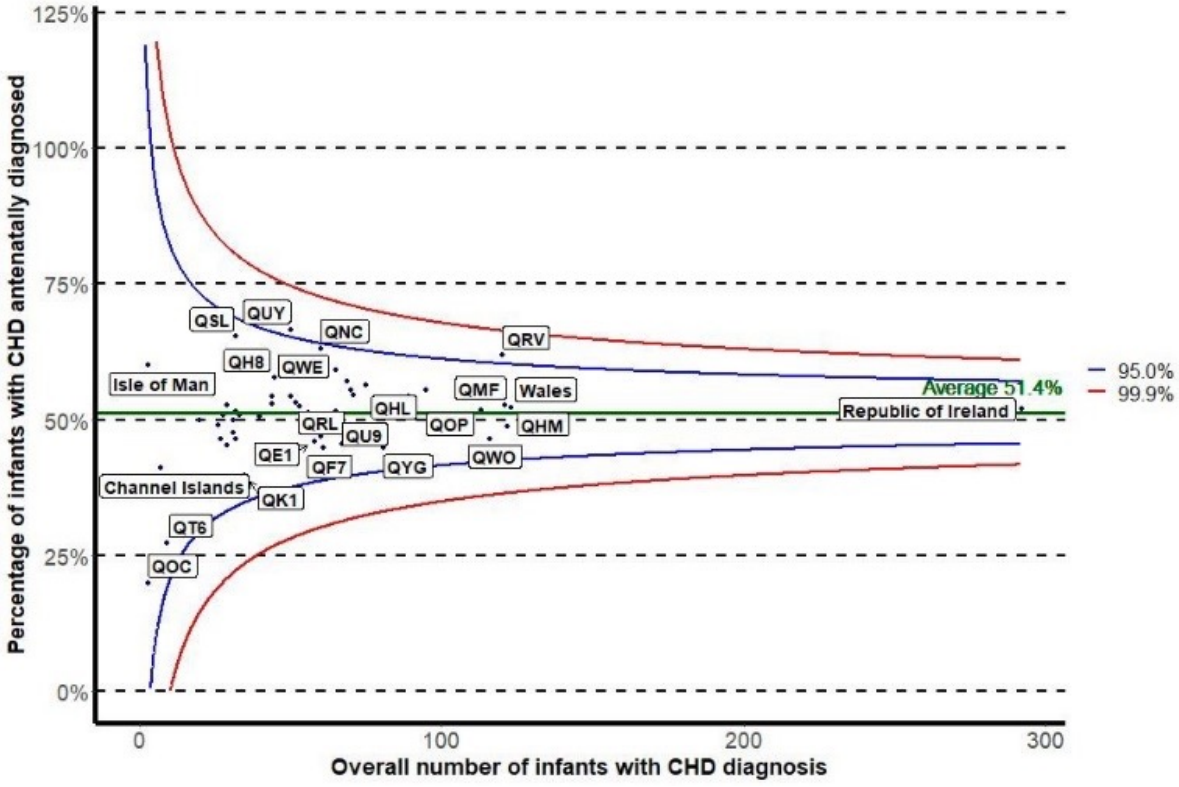
To understand and improve rates of detection and reduce regional variation, several steps should be considered:

- 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 3.9: Overall PPD rates by region for (a) 2019/22 and (b) 1-year overall PPD rates by region, 2021/22 [NCHDA data]**

a




b

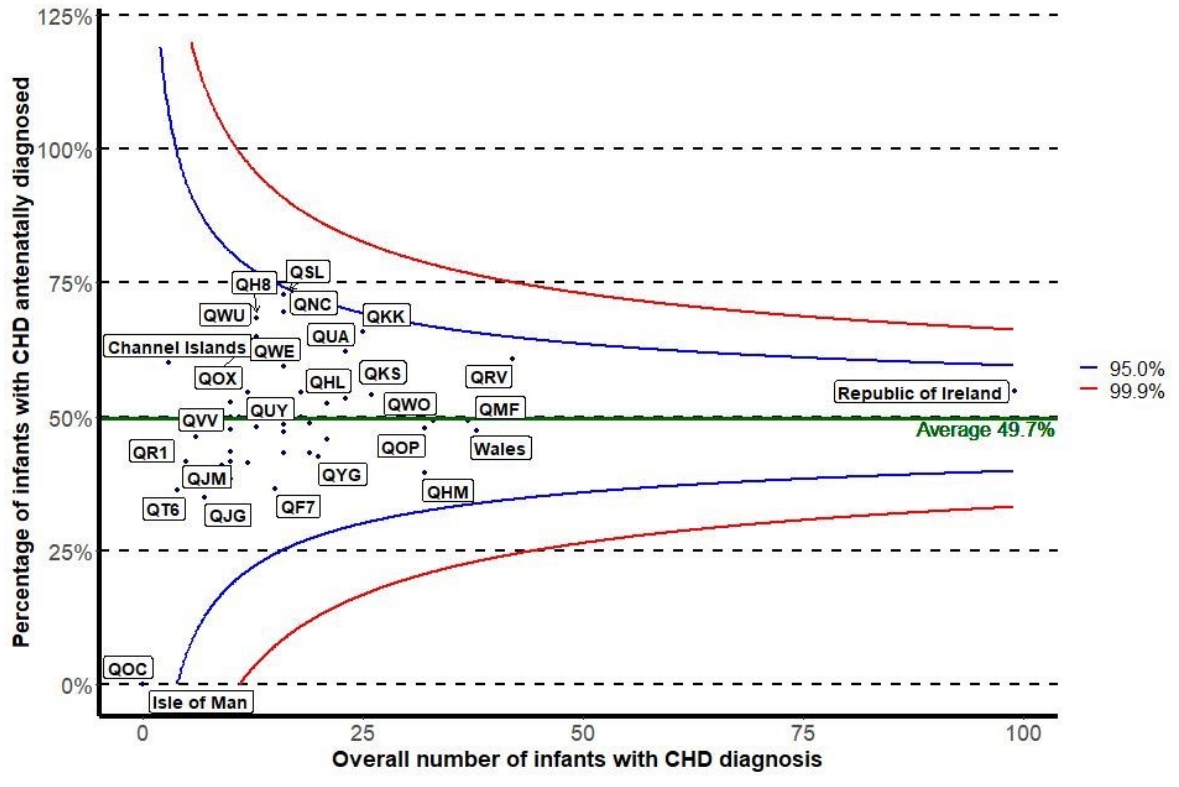
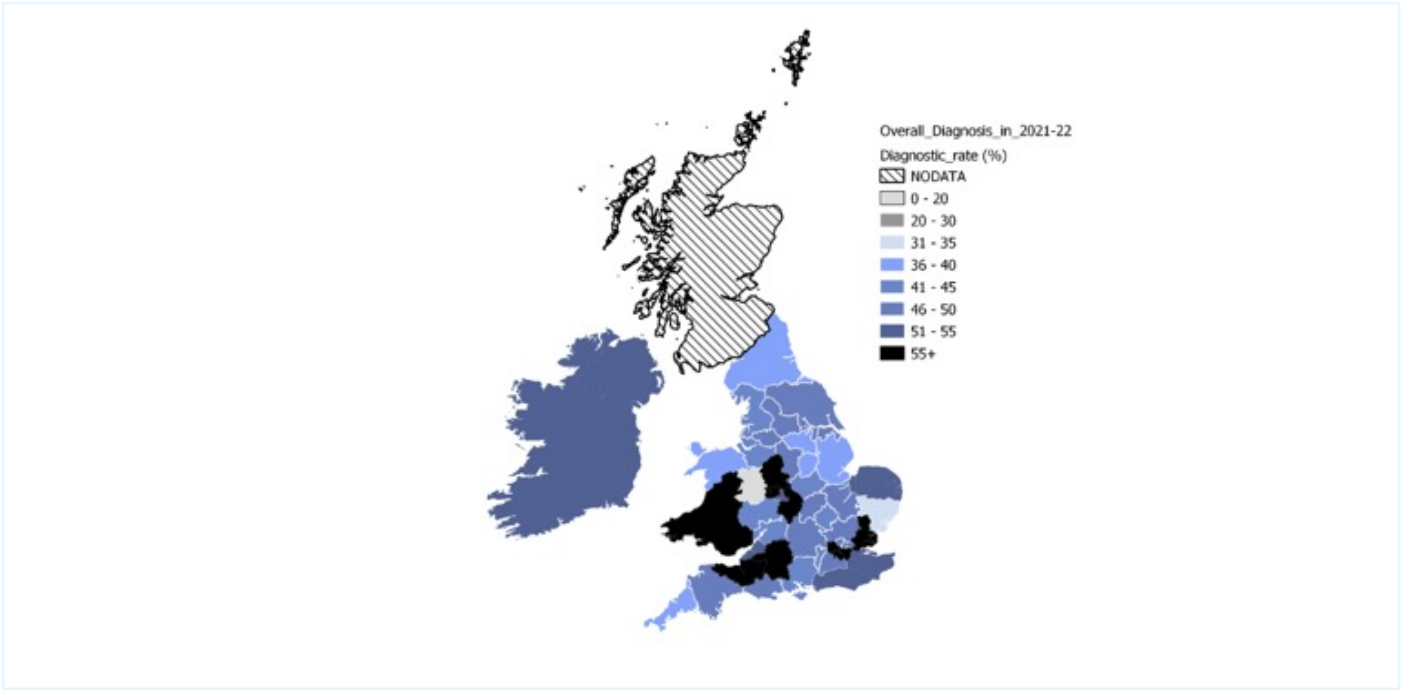


**Figure 3.10: Regional (ICS) and national variation antenatal diagnosis map for infants who underwent a procedure in the first year of life for any cardiac malformation, UK and Republic of Ireland (excluding Scotland), 2021/22 [NCHDA data]**




### 3.2.1.1 Detection rates for individual cardiac malformations

Table 3.8 shows the detection rate of four individual cardiac lesions. While prenatal screening continued throughout the pandemic, it is possible there was some disparity in the thresholds for detailed fetal echocardiography during this period and some expected natural variation would be expected. The detection of HLHS has dropped slightly compared to last year while the other three cardiac lesions show an upward trend in successful detection. We cannot be certain whether this represents a genuine fall in detection or whether, for example, there was an increase in the termination of pregnancy for this diagnosis. Linkage with the National Congenital Anomaly and Rare Disease Registration Service (NCARDS) would help clarify such issues. Interestingly, prenatal detection of lesions that would be detected on the 3VT view (TGA and TOF) have really improved (3VT view having been introduced in 2015).

The variation in overall diagnosis and detection of individual cardiac lesions is likely to be multifactorial:

**a.** Reduction in surgical activity, as data illustrate antenatally diagnosed patients having surgery within 12 months of birth.

**b.** Impact of the pandemic, which may have altered attendance rates for scans.

**c.** Variation in screening timing and methods, and especially in whether the 3VT screening view was used by sonographers.

**Table 3.8: Antenatal detection rates for HLHS, TGA-IVS, complete AVSD and tetralogy of Fallot for patients who underwent a procedure within 12 months of birth (2012/13 - 2021/22) in the UK and Republic of Ireland (not including Scotland), 2012/13 - 2021/22 [NCHDA data]]**

| Year | HLHS | TGA-IVS | Complete AVSD | Fallot | Overall |
|---|---|---|---|---|---|
| 2012/13 | 82.6% | 40.0% | 37.1% | 32.6% | 33.6% |
| 2013/14 | 79.8% | 38.6% | 35.7% | 40.3% | 38.2% |
| 2014/15 | 82.4% | 52.9% | 44.6% | 38.6% | 39.8% |
| 2015/16 | 86.2% | 54.7% | 43.6% | 41.5% | 41.8% |
| 2016/17 | 80.5% | 66.2% | 45.2% | 60.0% | 42.9% |
| 2017/18 | 87.3% | 74.6% | 56.5% | 63.4% | 51.9% |
| 2018/19 | 90.9% | 78.3% | 56.9% | 68.5% | 51.4% |
| 2019/20 | 87.7% | 77.4% | 61.0% | 68.4% | 51.9% |
| 2020/21 | 88.5% | 86.0% | 50.8% | 71.3% | 52.7% |
| 2021/22 | 82.8% | 86.3% | 56.7% | 79.7% | 50.4% |

A full table for diagnostic rates and funnel plots depicting the PPD rates by region for the three years 2019/20 to 2021/22 for the four CHD conditions (i.e. hypoplastic left heart syndrome, transposition of great arteries with intact ventricular septum, tetralogy of Fallot and complete atrioventricular septal defect (complete AVSD), for patients who underwent a cardiovascular procedure in the first year of life, is available here.

### 3.4.3 Recommendations for those not achieving the standard

Screening hospitals should aim to increase the rate of antenatal diagnosis of conditions requiring intervention in the first year. Individual congenital heart disease networks should improve rates of antenatal diagnosis by reviewing staffing, infrastructure, education and training requirements. There is a need for better linkage with the National Congenital Anomaly and Rare Disease Registration Service to optimise data quality and case ascertainment.

## 3.5 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.

### 3.5.1 Recommendations for those not achieving the standard

| 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%<br>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).<br>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 [24]<br>https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-Heart-Disease-Standards-Level-1-Specialist-Surgical-Centres-Adult.pdf[11] |
| **Numerator** | Depends on number of procedures the random sample patients have had within a 12-month time 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 time period – it can range from 20 - 35 procedures depending on complexity of sample. |
| **Trend** | Overall Good to Excellent:<br>• 11 centres score 98% or more<br>• 3 centres score between 95 – <98%<br>• 1 centre score 90 - <95% |
| **Variance** | This is difficult to quantify due to variation in case mix and numbers of procedures and infrastructure support, and Trend (above) can be an indicator of this.<br>Variance may also be due to inadequate, centre level, Database staff (Data Base Manager & support depending on size of centre), skillset, and in house software. |

## 3.5.2 **Audit results**

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.[18]

Table 3.9 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 3.9: Overall DQI for all centres submitting to NCHDA for 3 years, 2019/20 - 2021/22 [NCHDA data]**

| Paediatric/Mixed Practice Hospitals | Code | 2014-15 | 2015-16 | 2016-17 | 2017-18 | 2018-19 | 2019-20 | 2020-21 | 2021-22 | | Actual No of Whole Time Equivelants (WTE Data Managers for 2021-22) | NHSE Standards 2016 Requirement |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Belfast Royal Victoria | RVB | 98.75 | 98.25 | 94.50 | * | * | * | * | * | | see below | |
| Birmingham Children's Hospital | BCH | 98.50 | 97.75 | 99.50 | 99.00 | 99.00 | 99.00 | 99.50 | 99.50 | | 1.00 | 2 posts |
| Bristol Royal Children's Hospital | BRC | 94.50 | 98.60 | 98.75 | 99.00 | 99.50 | 99.25 | 99.50 | 99.75 | | 2.35 | 3 posts mixed practice |
| Dublin, Our Lady's Hospital | OLS | 97.25 | 94.50 | 97.00 | 98.25 | 99.00 | 99.00 | 98.50 | 99.25 | | 3.00 | 2 posts paeds only |
| Glasgow Royal Hospital for Sick Children | RHS | 98.50 | 99.25 | 99.25 | 99.50 | 99,50 | 99.00 | ** | ** | | no information | |
| Leeds General Infirmary | LGI | 97.00 | 97. 75 | 98.00 | 99.00 | 98.25 | 99.00 | 99.00 | 99.25 | | 2.00 | 3 posts mixed practice |
| Leicester Glenfield Hospital | GRL | 94.00 | 97.00 | 97.25 | 97.00 | 94.75 | 94.75 | 94.50 | 96.00 | | 1.50 | 3 posts mixed practice |
| Liverpool Alder Hey Childrens Hospital | ACH | 97.25 | 95.25 | 97.50 | 98.00 | 98.50 | 98.50 | 99.50 | 99.25 | | 1.25 | 2 posts |
| London Evelina Childrens Hospital | GUY | 97.50 | 99.25 | 96.00 | 99.00 | 99.40 | 97.75 | 98.75 | 99.75 | | 3.00 | 3 posts mixed practice |
| London Great Ormond Street | GOS | 99.50 | 97.00 | 99.50 | 95.00 | 93.00 | 97.75 | 98.50 | 99.25 | | 1.00 | 1 post paeds only within a team of 5 in information department |
| London Harley Street Clinic | HSC | 94.50 | 95.50 | 95.75 | 95.50 | ** | ** | ** | ** | | no information | |
| London Royal Brompton & Harefield | NHB | 99.00 | 99.25 | 99.25 | 99.00 | 87.50 | 95.75 | 98.00 | 94.75 | | 2.00 | 3 posts mixed practice |
| Newcastle Freeman | FRE | 97.25 | 97.50 | 99.00 | 98.75 | 99.00 | 99.75 | 99.80 | 99.50 | | 2.00 | 3 posts mixed practice |
| Southampton Wessex Cardiothoracic Centre | SGH | 97.50 | 95.75 | 99.00 | 98.75 | 98.75 | 98.25 | 98.75 | 98.25 | | 2.60 | 3 posts mixed practice |
| **Adult only Hospitals** | | | | | | | | | | | | |
| Belfast Royal Victoria | RVB | na | na | na | 95.00 | 96.00 | 96.75 | 98.00 | 98.75 | | 0.50 | 1 post |
| Birmingham Queen Elizabeth Hospital | QEB | 79.00 | 75.25 | 92.50 | 94.50 | 87.25 | 95.25 | 97.00 | 96.25 | | nil | 1 post |
| Glasgow Golden Jubilee | GJH | 94.50 | 92.50 | 99.00 | ** | ** | 98.00 | ** | ** | | no information | 1 post |
| Liverpool Heart & Chest Hospital | BHL | **** | **** | **** | **** | 93.50 | 94.75 | 98.75 | 99.25 | | 1.00 | 1 post |
| London University College/St Bartholomew's | UCL/SBH | 94.25 | 93.25 | 96.75 | 96.50 | 96.60 | 98.00 | 97.50 | 98.00 | | 1.00 | 1 post |
| Manchester Royal Infirmary | MRI | 97.00 | 97.70 | 98.50 | *** | *** | *** | *** | *** | | n/a | |
| | | | | | | | | | | | | |
| * ACHD only | | <90 | | | | | | | | | | |
| ** No data submitted | | 90 to <95 | | | | | | | | | | |
| *** Service transferred | | 95 to <98 | | | | | | | | | | |
| **** New Service | | >=98 | | | | | | | | | | |

# 4. Future direction

Over the next year, the NCHDA audit has the following aims:

- Encourage the use of the new online tools to improve data quality and allow hospitals rapid access to their own and benchmark performance data in as near to 'real-time' as possible
- Introduce new reporting tools. This will include dashboards and geographical mapping (e.g. to support regional reporting at ICS level)
- Revise/clarify definitions and to provide appropriate training to improve data quality and completeness through its Working Group
- Link with other datasets to establish new QI metrics for a more comprehensive review of clinical pathways
- Recalibrate the PRAiS risk model and review the criteria for the relevant variables
- Review the statistical methodology around the outlier process, focusing on specific procedures performed in low numbers
- Work with colleagues in Scotland to incorporate data from the audit there
- Consider the methodologies needed to report on long-term outcomes by diagnosis, collaborative initiatives to reduce early morbidity, and patient reported outcome measures (PROMs).

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# 6 Annex A: List of codes for participating centres 2021/22

| Code | Hospital |
|---|---|
| **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 |
| GUY | Evelina London Children's Hospital, London |
| LGI | Leeds General Infirmary |
| NHB | Royal Brompton Hospital, London |
| OLS | Our Lady's Children's Hospital, Dublin |
| SGH | Wessex Cardiothoracic Centre, Southampton General Hospital |
| **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 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 the 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 cardiolgy, through scientific and educational meetings.

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## 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.

National Cardiac
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# National Congenital Disease Audit (NCHDA)

## 2023 Summary Report (2019/20 - 2021//22 data)