NATIONAL CARDIAC AUDIT PROGRAMME

NATIONAL CONGENITAL HEART DISEASE AUDIT (NCHDA)

2022 Summary Report

(2020/21 data)

NICOR

National Institute of Cardiovascular Outcomes Research (NICOR)

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

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Society of Cardiothoracic Surgeons in Great Britain and Ireland (SCTS)

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.

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The Healthcare Quality Improvement Partnership (HQIP)

HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.

www.hqip.org.uk

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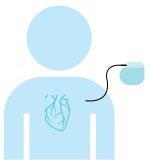
NCHDA AT A GLANCE

Data from the period April 2020 to March 2021

During the coronavirus disease (COVID-19) pandemic period there was a considerable fall in numbers of CHD procedures and increased waiting times, along with delays in outpatient appointments and other non-surgical activity. This effect was more pronounced in adults than children.

Number of treatments



There was a 17% reduction in overall activity (surgery, intervention and electrophysiology) with a total of 9,749 CHD procedures on children and adults in 2020/21.

All age groups were affected, with the largest fall in adult procedures (down 44%).

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 rose to 52% (though variations between centres showing scope for improvement).

Fetal anomaly screening continued nationally despite the pandemic.

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%.

Unadjusted raw (crude) 30-day mortality rate dropped to 1.6% of the 3,113 surgical operations undertaken in children under 16 years with a risk adjusted rate showing outcomes are better than expected.

There were approximately 10% fewer deaths than predicted after 30 days across 2,302 adult CHD operations.

Complications after procedures

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

Average complication rates include: 2.4% requiring life support, 1.5% requiring an unplanned pacemaker, 1.8% with prolonged pleural drainage and 4.1% needing renal replacement therapy (including peritoneal dialysis).

Executive summary

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

Congenital heart disease (CHD) is a heart condition or defect that develops in the womb before a baby is born, with CHD diagnosed in approximately 1 in 100 births.[1] Heart defects are the most common congenital anomaly in babies born in the UK and Ireland and they are the main cause of infant mortality due to a congenital anomaly. Over one quarter of CHD 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]

Today, at least 80% survive to adulthood and the population of adults with congenital heart disease (ACHD) is rapidly increasing, outpacing the relatively static prevalence of paediatric congenital heart disease.[3] The goal of congenital heart disease services is therefore to diagnose heart disease as early as possible and the ideal is before birth, referred to as antenatal diagnosis, as well as to provide excellent continuity of care as they progress through childhood and into adulthood.

The report covers the financial year 2020/21, during which the COVID-19 pandemic has challenged the capacity of healthcare systems around the world, including substantial disruptions to cardiovascular care across key areas of healthcare delivery. The imposed measures and relentlessly stretched healthcare resources have had a considerable impact on the care of CHD patients and the report considers the impact of COVID-19 on paediatric and adult CHD activity in this difficult period.

The report also focuses on a number of specific quality improvement (QI) metrics in relation to the delivery of CHD services derived from national and/or international standards and guidelines. By robust analysis of audit data and comparing patient outcomes, such as case-mix adjusted survival, the aim is to improve the quality of care received by patients from UK (excluding Scotland) or Ireland, hospital admission to discharge, and ensuring they meet good practice standards.

WHERE THINGS WORSENED / CAUSES FOR CONCERN	
Overall, the pandemic has significantly affected all aspects of CHD activity	Patients with increasing severity of complex CHD (e.g. Fontan circulation) are linked to a higher risk of COVID-19 related complications and associated mortality. Considerable fall in numbers of CHD procedures and increased waiting times. Delays in outpatient appointments, elective investigations and other non-surgical activity. Impact more pronounced in adults compared to children.
A significant drop in overall activity in all age groups	17% reduction in overall activity (surgery, intervention and electrophysiology) with a total of 9,749 CHD procedures undertaken on children and adults in 2020/21. All age groups affected, with the largest fall in adult procedures (down 44%).
Post-procedure related complication rates for under-16s show some variation	Some inter-centre variance is seen in the incidence of each complication. The significance of these results is not yet known. Average complication rates include: 2.4% requiring life support, 1.5% requiring an unplanned pacemaker, 1.8% with prolonged pleural drainage and 4.1% needing renal replacement therapy (including peritoneal dialysis).

WHERE LEVELS OF CARE WERE MAINTAINED OR REMAINED STABLE	
Data quality high	Overall data quality indicator (DQI) scores were very good.
WHERE THINGS IMPROVED / PRACTICES CHANGED	
Antenatal diagnosis improved	Antenatal diagnosis for all infants requiring a procedure in the first year of life rose to 52% (though variations between centres showing scope for improvement). Fetal anomaly screening continued nationally despite the pandemic.
Excellent surgical outcomes in children better than predicted	Outcomes after paediatric cardiac surgery continue to show a high 30-day survival rate of over 98%. Unadjusted raw (crude) 30-day mortality rate dropped to 1.6% of the 3,113 surgical operations undertaken in children under 16 with risk adjusted rate showing outcomes are better than expected. Risk-adjusted analysis showed outcomes are better than expected.
Very good 30-day survival in adults	Approximately 10% fewer deaths than predicted across 2,302 adult CHD operations.

Summary of recommendations

1. The NCHDA has made significant progress with the development of better definitions with the aim to help centres accurately record post-procedural complications, allowing consistent data submission and analysis of early morbidities associated with cardiac surgery.
2. 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.

1 Introduction

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

Congenital heart disease (CHD) is a heart condition or defect that develops in the womb before a baby is born, with CHD diagnosed in approximately 1 in 100 births.[1] Heart defects are the most common congenital anomaly in babies born in the UK (excluding Scotland) and Ireland and they are the main cause of infant mortality due to a congenital anomaly. Over one quarter of CHD 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]

The prevalence of congenital heart disease (CHD) has changed over the past decades as improved survival has led to an increasing number of people living with CHD in adulthood.[1] In the UK, CHD is one of the most common types of birth defects, affecting about 8 per 1000 live births. Survival has significantly improved and consequently led to an increasing population of adults with congenital heart disease (ACHD).[4]

Today, at least 80% survive to adulthood and the population of adults with congenital heart disease is rapidly increasing, outpacing the relatively static prevalence of paediatric congenital heart disease.[3] The goal of congenital heart disease services is therefore to diagnose heart disease as early as possible and the ideal is before birth, referred to as antenatal diagnosis, as well as to provide excellent continuity of care as they progress through childhood and into adulthood.

The main purpose of the National Congenital Heart Disease Audit (NCHDA) is to provide assurance about the quality of CHD services by examining service delivery for, and outcomes of infants, children, adolescents and adults undergoing interventions for paediatric and congenital heart disease. The audit 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). It broadly follows the clinical pathway from patient admission to hospital discharge with the aim to review and reflect on the changing needs of congenital heart services. Data are submitted from all centres in the UK and the Republic of Ireland other than in Scotland. In 2020, Public Health Scotland made a decision to withdraw participation and data submission to the National Cardiac Audit Programme. This report does not include Scottish data in all analyses undertaken for the period from 2011/12 to 2020/21 and so some data will be different to data in previous reports.

Congenital heart disease services are a relatively small specialty accounting for just over 1% of the NHS specialised commissioning budget.[5] Because of the relatively small number of cases involved with a large number of different procedures, the audit provides composite outcome analyses, to both allow meaningful comparison of units and minimise the risk of identifying individuals. This is in line with the Office for National Statistics (ONS) Confidentiality Guidance for publishing health statistics.

The report covers the financial year 2020/21, during which the COVID-19 pandemic has challenged the capacity of healthcare systems around the world, including substantial disruptions to cardiovascular care across key areas of healthcare delivery. The imposed measures and relentlessly stretched healthcare resources have had a considerable impact on the care of CHD patients and the report considers the impact of COVID-19 on paediatric and adult CHD activity in this difficult period.

The report also focuses on a number of specific quality improvement (QI) metrics in relation to the delivery of CHD services derived from national and/or international standards and guidelines. By robust analysis of audit data and comparing patient outcomes, such as case-mix adjusted survival, the aim is to improve the quality of care received by patients from UK or Ireland hospital admission to discharge and ensuring they meet good practice standards. Information on the methodology underpinning the audit, detailed background for all QI metrics and additional data analyses can all be found here.

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

The rest of this report is structured as follows:

- **Section 2** highlights the principal impacts of the COVID-19 pandemic
- **Section 3** focuses on a small number of Quality Improvement (QI) metrics which should continue to be a priority, either for teams within hospitals or for those leading service commissioning and development at Integrated Care System (ICS) level
- **Section 4** provides some pointers towards the future direction of the audit

2 Principal impacts of the COVID-19 pandemic

Since December 2019, severe acute respiratory syndrome corona virus 2 (SARS-CoV-2) or coronavirus disease (COVID-19) has caused significant morbidity and mortality globally.[6] The last 2 years of the COVID-19 pandemic have had a massive impact on healthcare systems, diverting resources away from routine hospital services as they remain stretched and overwhelmed from the burden of infection.

Early data on COVID-19 identified heart disease as a risk factor for mortality.[6,7] There are limited data on the effects of COVID-19 on paediatric and adult congenital heart disease patients, although CHD with increasing complexity is likely to represent a high-risk group.[8,9] The severity of CHD depends on not only the complexity and heterogeneity of cardiac anatomy and physiology but also on the status of surgical repair, comorbidities, associated genetic anomalies and additional variables like presence of arrhythmia, end-organ dysfunction, exercise capacity, pulmonary hypertension, hemodynamically significant shunt, etc.

Congenital heart disease is one example of a chronic, life-long condition with a spectrum of severity from mild to life-threatening. It represents the most common birth defect and significant improvements in diagnosis and treatment mean that currently approximately 12 million people live with CHD worldwide.[10] Both paediatric and adult patients typically require regular follow-up with specialist CHD professionals and tests of cardiac function are a cornerstone of follow-up.[11,12] But, as with other patient groups during the pandemic, services for patients with CHD have seen significant and abrupt changes since March 2020.

2.1 Overall, the pandemic has significantly affected all aspects of CHD activity

Early data showed the pandemic affected children less than adults, with less than 2% cases in Europe occurring in children younger than 18 years.[14,15] Currently, it is unclear whether this is due to lower infection susceptibility in children or if the asymptomatic disease is much more common in those under the age of 18 years.[16,17] Our data clearly highlight that the impact of the pandemic on services for congenital patients was more profound in adults when compared to children.

Given the experience in patients with CHD globally, there were concerns that those with severe CHD would be at a particular high risk from COVID-19.[18,19,20] On March 18th 2020, the British Congenital Cardiac Association issued a statement to identify vulnerable patients with CHD,[21] categorising them into high and low risk groups. In addition to the cardiac morbidity, many patients with CHD also have other organ involvement including chronic lung disease, cirrhosis and renal disease, which may increase the risk of COVID-19.[22]

Like many countries, the periods of lockdown in the UK & RoI led to cessation of non-essential face-to-face patient contact, necessitating rapid adjustments and adaptation to new ways of delivering and receiving care. Most tertiary cardiac centres and congenital cardiologists and surgeons had to shift their focus of care, postponing or re-routing specialised cardiac procedures to provide adequate

Table 2.1: Headlines of COVID-19 impact

Key areas of CHD affected	Reduction in activity in 2020/21 from 2019/20
Overall procedural activity	17%
Surgical activity children	18%
Surgical activity adults	44%
Overall Catheter/EP activity	16%
Non-cardiac effects	Psychological and mental health issues[13], anxiety around COVID-19 related myocarditis, information about vaccinations.

resources for general COVID-19 patients. Within CHD, the impact of these changes has led to delayed diagnosis of progressive or new disease, delays in seeking treatment, cancellations of treatment, greater non-adherence to medical therapy as well as increased mental health problems.[13]

In response to the pandemic crisis, 2 major CHD centres – Glenfield Hospital (Leicester) and Royal Brompton Hospital (London) were converted to ExtraCorporeal Membrane Oxygenation (ECMO) support units for COVID-19 patients and all cardiac procedural activity were moved to Birmingham Children's Hospital and Evelina London Children's hospital respectively. The pandemic affected all CHD centres both in terms of volume and complexity of cases treated, leading to the majority of elective surgeries being either postponed or cancelled. The disruption in CHD services was further compounded by a reduction in staff and limited availability of resources. The report highlights the significant impact on surgical and interventional procedure volumes and case-mix across all centres nationally.

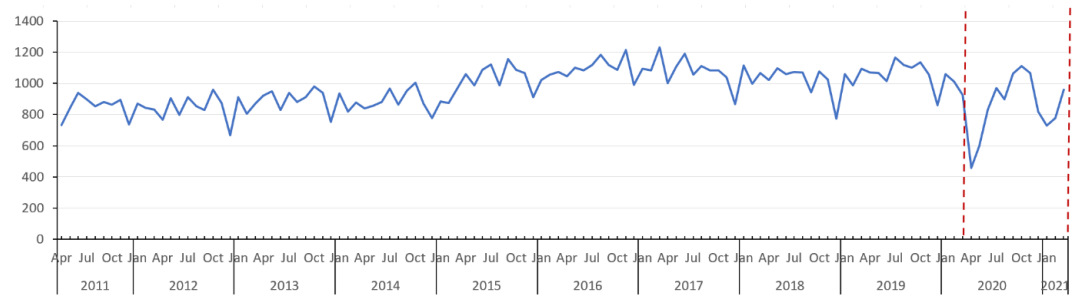
2.2 The pandemic significantly reduced CHD procedural activity

During the peak of the pandemic's first wave between April and June 2020 with the first nationwide lockdown, CHD procedural activity suffered the most significant impact as shown in Figure 2.1. Further impact on activity can be seen following the second wave and lockdown between January and March 2021. There was a major fall in overall procedural activity in all age groups by around 17% in 2020/21 when compared to 2019/20 with surgical activity reduced by around 18%.

Figure 2.2 shows 10-year monthly trends for individual procedures, demonstrating a significant drop during both pandemic waves.

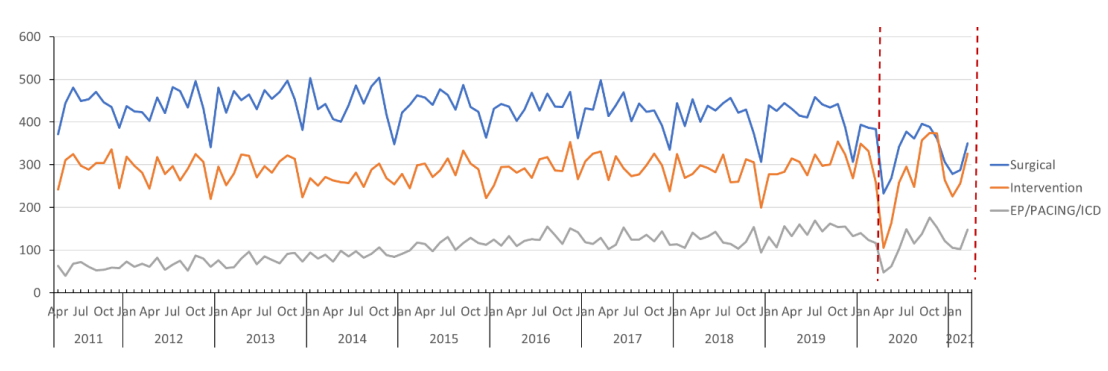
When the data were further split by age groups, the reduction in procedural activity significantly affected children and adult groups, while neonates and infants

Figure 2.1: 10-year trends in overall monthly procedure activity (surgical, interventional catheter and electrophysiological procedures), all ages from 2011/12 to 2020/21 [NCHDA data]



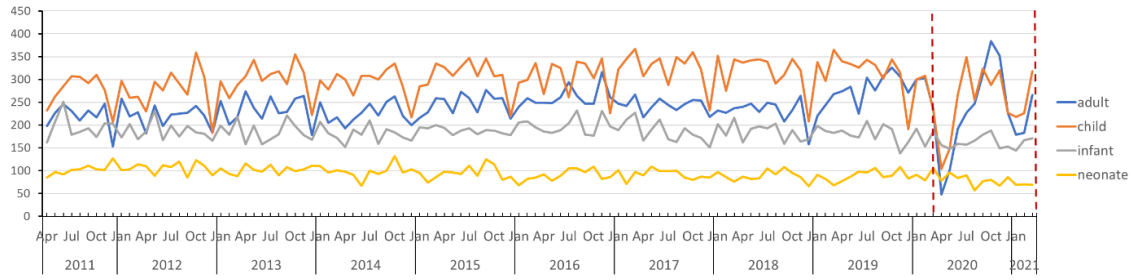
Note: Data from Scottish centres were excluded for all years. Dotted lines highlight period between first and second lockdown period during the COVID-19 pandemic.

Figure 2.2: 10-year trends in monthly surgical, interventional and electrophysiological procedures, all ages from 2011/12 to 2020/21 [NCHDA data]



Note: Data from Scottish centres were excluded for all years. Dotted lines highlight period between first and second lockdown period during the COVID-19 pandemic.

Figure 2.3: 10-year trends of overall monthly procedural activity, split into four age groups from 2011/12 to 2020/21 [NCHDA data]



Data from Scottish centres were excluded for all years. Dotted lines highlight period between first and second lockdown period during the COVID-19 pandemic.

were less impacted. This trend is explained by the fact that while most elective procedures were postponed or cancelled, urgent and emergency procedures (more commonly performed in neonates and infants) continued to be undertaken as shown in Figure 2.3.

It is possible that, for some patients, the delay in offering an elective procedure led to progressive clinical deterioration warranting an urgent or emergency procedure.

2.3 Non-procedural CHD activity was also reduced or delayed

2.3.1 Reduced hospital appointments and increased waiting times

The significant risk posed by SARS-CoV-2 and unprecedented demand for hospital resources for COVID-19 patients led to radical actions to mitigate the impact of the pandemic. The UK government introduced several measures from social distancing requirements and facemask use, including extreme measures like strict nationwide lockdown and shielding guidelines for vulnerable patients. These actions had a major impact on CHD patients and meant that in-person hospital visits were widely switched to audio-video consultations. It is important to highlight that unlike other specialities, clinical examination, electrocardiogram (ECG) and echocardiography are crucial for cardiac assessment in CHD patients, and this was not possible with virtual consultations.

Reduction in elective hospital appointments resulted in a significant increase in patient waiting times for face-to-face outpatient clinics, review of new patients, delays in investigations like echocardiography, cross-sectional imaging (CT or MRI), exercise tests, routine assessments and allied clinical support including dentistry. These delays then impacted on the timeliness of elective procedural activity and may have resulted in some procedures being converted to urgent or emergency cases.

2.3.2 Antenatal screening was maintained

During the pandemic, the mid-trimester anomaly scan continued to be offered to all pregnant women. The cardiology services also continued to provide assessment by a fetal cardiologist when there was a finding of a possible fetal heart anomaly – allowing a definitive diagnosis to be made and a management pathway for the pregnancy agreed. In addition, appropriate counselling and support for the parents and the coordination of postnatal care occurred, with many teams having to adapt their way of working with virtual consultations and meetings. Due to limits on people allowed into hospitals, sometimes counselling occurred in the absence of partners, or with partners having to listen virtually, which was challenging and not ideal.

Of neonates undergoing a cardiac intervention in the first year of life, the audit data showed a very small dip from 51.4% having a prenatal diagnosis in 2018/19 to 49.8% in 2019/20. However, in 2020/21 this increased to 52.3%. This is a very commendable achievement considering the pressures brought by the pandemic. This is likely to reflect that routine antenatal obstetric screening was maintained during the pandemic.

At the beginning of the pandemic, in many centres, there was a temporary suspension of fetal cardiology specialist scans of women considered to be at increased risk of having a fetus with congenital heart

disease. In most centres, these women had a routine anomaly scan in their local unit and were only referred to fetal cardiology if an abnormality was suspected. For these women, there was a balance of risk between patients travelling and attending a hospital, risking COVID-19 infection, and a potentially beneficial scan, which however had a relatively low yield for detection of abnormality.

2.3.3 Staff have been profoundly affected

The severity and duration of the pandemic have left a long-lasting and profound impact on all healthcare staff, and left many with physical, mental and emotional ramifications. As a consequence, this has affected staff well-being, engagement, sickness or absence rates and is having an effect on staff retention. Staff who developed COVID-19 had to follow quarantine and isolation guidelines and this put additional pressure on the active work force.

Whilst the majority of urgent CHD procedures were unaffected, the reduction in staff was one of the factors behind the postponement or cancellation of elective procedures. Others included a lack of bed availability, staff redeployment and COVID-19 infections in patients and families.

2.3.4 There were widespread concerns and impacts amongst patients and parents

The COVID-19 pandemic caused a dramatic prolonged effect on our entire society. While specific impacts of this disease in congenital heart disease patients have been less severe (compared to certain populations like elderly patients with significant co-morbidities), feedback from several centres have expressed a widespread concern about the virus amongst parents of children with CHD and ACHD patients.

Most patients/parents were concerned about the potential effects of the virus on those with CHD and how they would cope with varying severity of the disease. While there was a lot of information about adults with cardiovascular disease, there was little information available specific to congenital heart disease patients. However, parents acknowledged the access to information from a number of sources such as the British Congenital Cardiac Association (BCCA), British Heart Foundation (BHF) and CHD local and national charities. Specific on-line patient groups were created by individual centres with help of cardiac specialist nurses and parent/patient representatives, to address some of the concerns that families had.

Parents and patients were also concerned about mixed messaging and a lack of clarity around guidelines on shielding during the initial lockdown, vaccination policy in different age groups and complexity of CHD and vaccine-related complications. The inability to be seen in person for clinic appointments was also a key point of concern. Parents with children who were awaiting procedures felt particularly anxious and worried about cancellations and how this would impact on their cardiac condition.[23] Some patients were terrified of attending hospital due to the fear of contracting the virus, leading to failure to attend appointments.

2.3.5 Learning and new practices have emerged

Bringing about change is not always a bad thing. The pandemic has made us rapidly adapt to the new reality of delivering healthcare. Acknowledging the major efforts and commitment of staff throughout the NHS to tackle the impact of COVID-19, specialised health care areas like CHD have been through a very challenging period over the last year. Like most areas of hospital care, CHD patients and staff had little choice but to embrace digital solutions for ongoing care.

The NHS has made great strives to incorporate the use of advanced digital technology to improve quality and efficiency. These include:

- Phone and video consultations (e.g. Attend Anywhere, vCreate), remote patient monitoring
- NHS app for appointment booking and patient access records
- Video conferencing software for professional MDTs (e.g. Microsoft Teams, Zoom)
- E-prescribing
- On-line support groups

As we move into the recovery phase of the pandemic and focus our efforts for future planning, NHS services will have to adapt to the shifts in the care system and implement new ways of working. The key strategies would be to have greater collaboration between primary, secondary and tertiary care allowing better streamlining of specialist services like CHD. The use of innovative technology and addressing barriers like risk of digital exclusion would be instrumental in creating a model of sustainable change within the healthcare services.[24]

3 | Quality Improvement Metrics

3.1 Congenital Heart Disease Procedural Activity

Approximately 10,000 procedures in children and adults were submitted to the NCHDA in 2020/21. The volume of procedures carried out can be a significant factor in developing the necessary skills and infrastructure for treating patients with congenital cardiac malformations. As with the other audits, it is generally accepted that performance improves the more one practices a specific skill – 'practice makes perfect' – and professional societies, regulators and commissioners have recommended certain minimum volumes of activity at hospitals for particular services, including congenital heart disease, as set out in NHS England's 2016 Standards and Services Specification.[25,26]

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[25] 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, and by the Royal College of Surgeons. Congenital Heart Disease Services: Decision Making Business Case November 2017: main document.[27] Congenital Heart Disease Services: Decision Making Business Case November 2017: Annex B, page 358 (Appendix 1, Annex 6).[27]
Numerator	NHSE countable surgical procedures – for neonate, child and adults.
Denominator	NHSE countable surgical procedures.
Trend	Overall activity dropped by 17% when compared to 2019/20. All surgical activity reduced by 18% with the most significant drop seen in adult congenital heart surgery (by 44%) [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 of the pandemic causing a drop in all types of procedures. In Figure 3.3, the data are split by age groups, with 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

In 2020/21, UK and Republic of Ireland centres (excluding Scottish centres) submitted data on 9,749 procedures where 6,727 were paediatric cases and 3,022 were adult congenital heart cases as shown in Table 3.1 below. Due to the COVID-19 pandemic, overall activity for 2020/21 has significantly fallen for all procedures and all age groups as shown in Table 3.1.

Table 3.1: CHD activity by age group – All Procedures (2020/21) [NCHDA data]

	Procedures (All ages)	Procedures (Under 16 years)	Procedures (16 years and older)
Overall activity	**9,749**	**6,727**	**3,022**
Surgical procedure activity			
Surgery undertaken using cardiopulmonary bypass	3,170	2,671	499
Surgery undertaken without using cardiopulmonary bypass (including surgical EP)	663	602	61
Hybrid procedures	57	53	4
Primary ECMO	47	4*	<3
Ventricular Assist Device (VAD)	14	1*	<3
Total	**3,951**	**3,384**	**567**
Catheter procedure activity			
Interventional catheterisation procedures	3,174	1,901	1,273
Diagnostic catheter procedures	1,202	823	379
Total	**4,376**	**2,724**	**1,652**
Electrophysiological activity (non-surgical)			
Implantable Cardioverter Defibrillator (ICD)	134	48	86
Pacemaker procedures	388	112	276
EP ablation and EP diagnostic procedures	900	442	458
Total	**1,422**	**602**	**820**

Note: Activity numbers are those procedures agreed by NHS England to be 'countable' towards individual operator activity (data from Scottish centres excluded). 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 procedure: the procedure is undertaken in isolation and not as a support operation after another congenital heart procedure (these are considered post-procedural complications); this excludes ECMO for primary respiratory failure.

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

Table 3.2: Percentage drop in procedural activity in 2020/21 when compared with 2019/20, by procedure type and age groups [NCHDA data]

Year	All age groups				Children (<16 years)				Adults			
	Total	Surgery	Catheter	EP	Total	Surgery	Catheter	EP	Total	Surgery	Catheter	EP
2020/21	9,749	3,951	4,376	1,422	6,727	3,384	2,724	602	3,022	567	1,652	820
2019/20	11,803	4,806	5,184	1,726	7,850	3,800	3,208	758	3,953	1,006	1,976	968
% reduction	17	18	16	18	14	11	15	21	24	44	16	15

Note: Data from hospitals in Scotland have been excluded from each year.

A full breakdown of 30-day outcomes by age group for all procedures (2018/19 to 2020/21) as well as a breakdown of activity for centres undertaking major congenital cardiac procedures (2018/21) for children and adults in the UK can be found here.

Table 3.3 shows 10-year trends for CHD procedures, split by procedure type, and Figure 3.1, Figure 3.2 and Figure 3.3 show 10-year quarterly temporal trends highlighting a significant drop in quarterly activity during the pandemic.

When the data were further split by age groups, the reduction in procedural activity significantly affected children and adult groups while neonates and infants were less impacted as shown in Figure 3.3.

Table 3.3: Total number of cases categorised by type of procedure submitted to the NCHDA for financial years 2011/12 – 2020/21 [NCHDA data]

Year	Surgical	Hybrid	Interventional catheter & EP procedures			Diagnostic Catheter	Total
			EP/Pacing	ICD	Intervention		
2011/12	5,198	26	662	68	3,553	—	9,507
2012/13	5,301	15	731	81	3,370	—	9,498
2013/14	5,405	49	892	102	3,452	—	9,900
2014/15	5,194	60	997	116	3,245	—	9,612
2015/16	5,231	55	1,287	119	3,441	1,608	11,741
2016/17	5,212	46	1,393	150	3,631	1,746	12,178
2017/18	4,957	78	1,383	109	3,460	1,628	11,615
2018/19	4,935	73	1,366	133	3,375	1,500	11,382
2019/20	4,812	81	1,567	158	3,705	1,480	11,803
2020/21	3,894	57	1,288	134	3,174	1,202	9,749
Total	**50,139**	**540**	**11,566**	**1,172**	**34,407**	**9,164**	**106,988**

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 hospitals in Scotland have been excluded from each year.

Figure 3.1: 10-year quarter trends of surgical, interventional catheter and electrophysiological procedures at all ages for financial years 2011/12 – 2020/21 [NCHDA data]

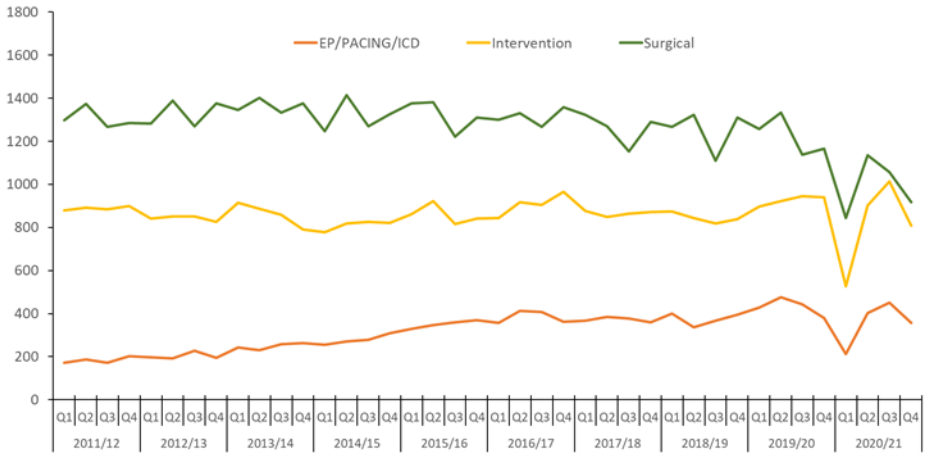


Figure 3.2: Procedural activity changes in Q1 by types (2011/21 – 2020/21) [NCHDA data]

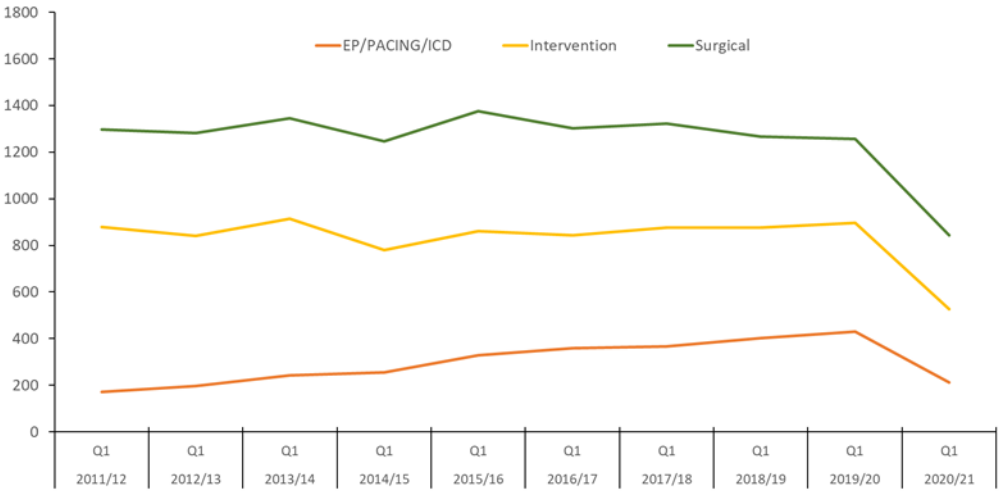
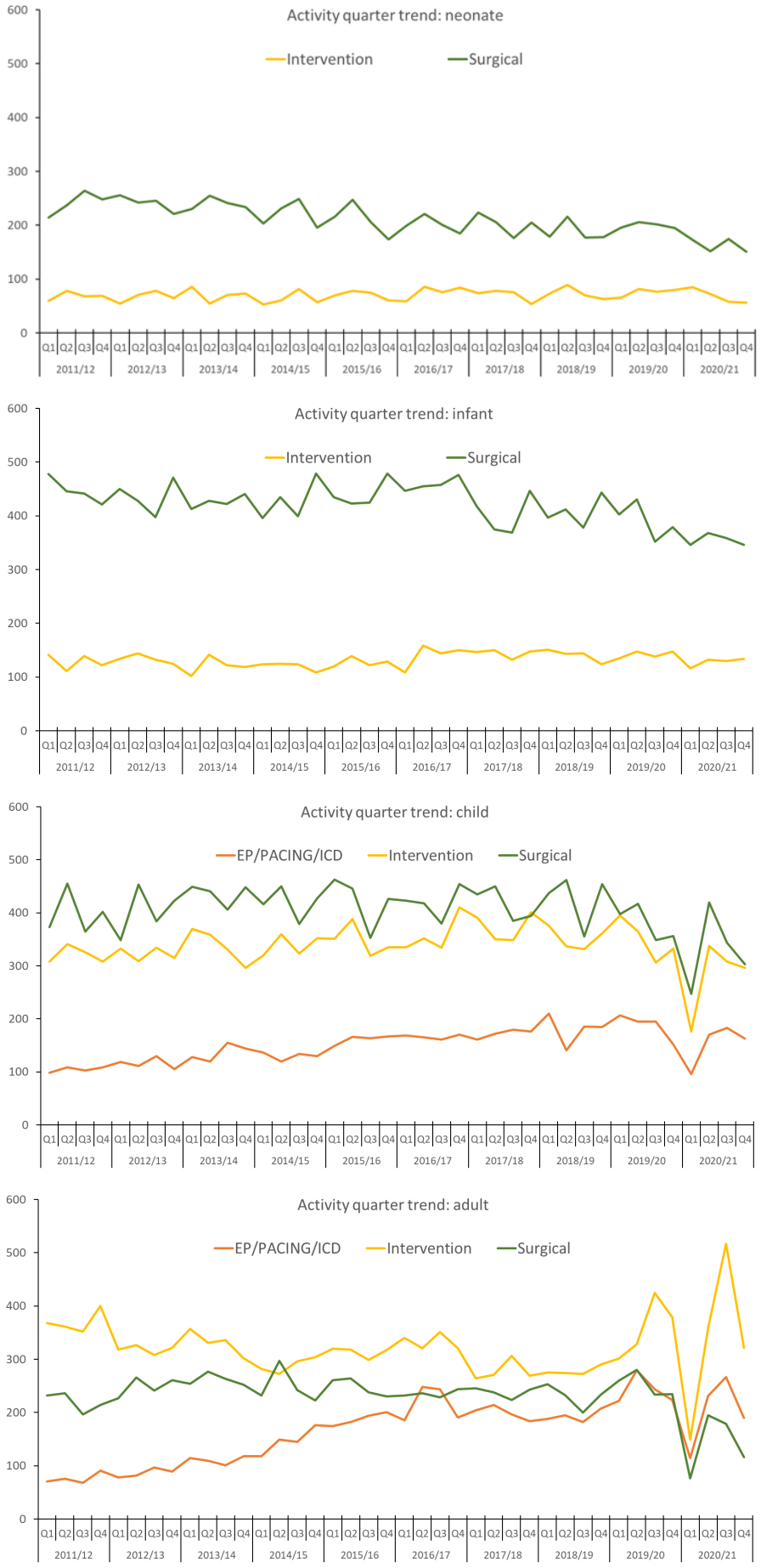


Figure 3.3: 10-year quarter trends in surgical, interventional catheter and electrophysiological procedures, all ages for financial years 2011/12 – 2020/21 [NCHDA data]



3.2 Procedural mortality remains low

Hospitals providing care for children and adults with CHD have low levels of 30-day mortality. Despite this being one of the most complex areas of surgery and lifesaving for congenital patients, the UK and Republic of Ireland continue to have excellent outcomes with high survival and low mortality rates. The NCHDA uses two risk models for assessing outcomes:

- Partial Risk Adjustment in Surgery (PRAiS) model for children[28,29]
- Society of Thoracic Surgeons – European Association for Cardio-thoracic Surgery (STAT) mortality score for adults (16 years and over)[30]

3.2.1 Overview of QI metric: Summary of 30-day Mortality pertaining to aggregated and specific procedure outcomes, 2018/21

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 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. • 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 83 specific CHD procedures 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.[28] • Improving risk adjustment in the PRAiS model for mortality after paediatric cardiac surgery and improving public understanding of its use in monitoring outcomes.[29] • 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.[30]
Numerator	Number of patients whose death is recorded by centre or ONS linkage.
Denominator	Total expected risk adjusted mortality.
Trend	Overall non-risk adjusted 30-day mortality remains low at 1.6% and risk-adjusted survival was much better as illustrated in Figure 3.4 and Figure 3.5.
Variance	Analysis is on-going of 30-day mortality outcomes following the 83 specific procedures, or aggregated surgery in children or adults with CHD.

3.2.2 Audit Results

3.2.2.1 30-Day Aggregate Survival after Surgery in Children

Specialist centres use Variable Life Adjusted Displays (VLAD), depicting the predicted minus the actual number of survivals at 30 days post-surgery, as well as re-interventions within 30 days of the surgery, to monitor their own outcomes [Figure 3.4]. The benchmarking in the VLAD is based on the Partial Risk Adjustment in Surgery (PRAiS) model, which was revised and improved in June 2016 (PRAiS2), as well as recalibrated using the 2009/10–2015/16 Congenital Audit outcomes, with improved statistical performance.[28]

The VLAD chart line in Figure 3.4 shows the national outcomes between 1 April 2018 and 31 March 2021. There is a continuing upward trend over 2020/21 suggesting that, in spite of the impact of the pandemic, actual results were outperforming those expected.

The crude unadjusted mortality for surgical procedures in children over the last 10 years is shown in Figure 3.5. In the context of the 18% drop in surgical activity in 2020/21, the mortality was 1.6% for 3113 surgical procedures undertaken in children under 16 years of age. The risk-adjusted 3-year results for each centre are shown in Figure 3.6. We also ran the PRAiS by year (2018/19, 2019/20, and 2020/21), which showed that the overall ratio of survival (98.4%) in 2020/21 was slightly higher than the risk predicted survival (98%).

Figure 3.4: Variable Life Adjusted Display (VLAD) Chart for all 11 paediatric centres in the UK and Republic of Ireland (Excluding Scottish centres) undertaking procedures in patients under 16 years of age, 2018/19 – 2020/21 [NCHDA data]

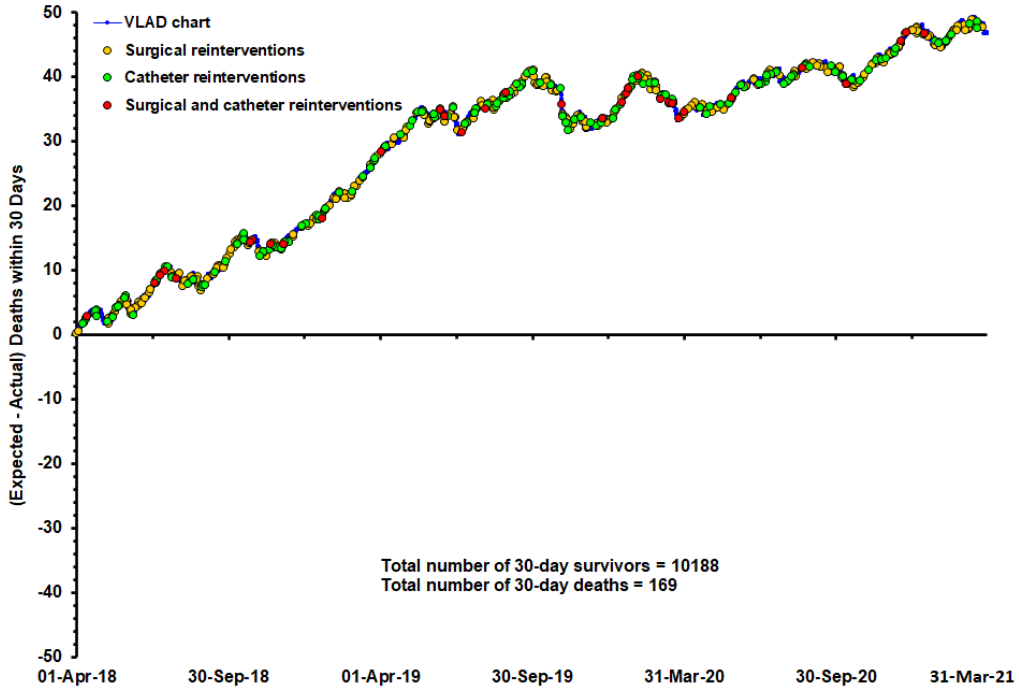


Figure 3.5: 30-day unadjusted mortality (%) in children (under 16 years) after surgery over 10 years, 2010/11 – 2019/20 [NCHDA data]

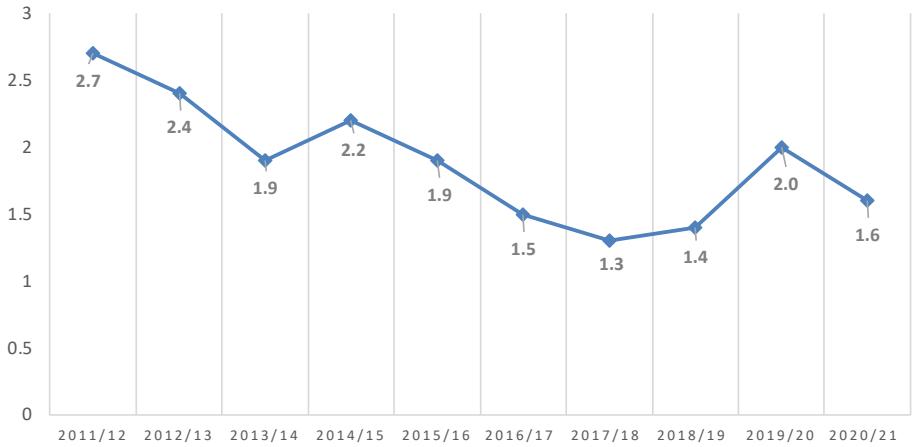
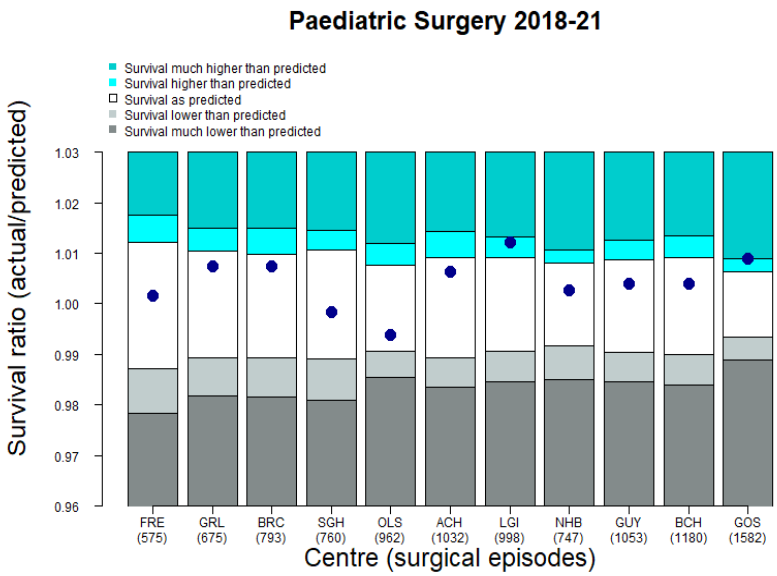


Figure 3.6: Actual vs Predicted Survival for all 11 centres undertaking cardiac procedures in patients under 16 years of age in the UK and Republic of Ireland (excluding Scottish centres), using PRAiS2 risk adjustment methodology, 2018/21 [NCHDA data]



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

Table 3.4: Actual and Predicted Survival, using PRAiS2 Risk Adjustment methodology with average predicted risk per case, for all 11 units undertaking procedures in patients under 16 years of age, 2018/21 [NCHDA data]

Hospital	Surgical Episodes	Survivors	Deaths	Actual Survival	Predicted Survival	Actual/ Predicted	Average Risk per case
FRE	575	562	13	97.74%	97.59%	1.002	2.41%
GRL	675	667	8	98.81%	98.08%	1.007	1.92%
BRC	793	781	12	98.49%	97.77%	1.007	2.23%
SGH	760	742	18	97.63%	97.78%	0.998	2.22%
OLS	962	939	23	97.61%	98.21%	0.994	1.79%
ACH	1,032	1,012	20	98.06%	97.45%	1.006	2.55%
LGI	998	988	10	99.00%	97.81%	1.012	2.19%
NHB	747	739	8	98.93%	98.67%	1.003	1.33%
GUY	1,053	1,034	19	98.20%	97.81%	1.004	2.19%
BCH	1,180	1,154	26	97.79%	97.41%	1.004	2.59%
GOS	1,582	1,570	12	99.24%	98.37%	1.009	1.63%
Overall	**10,357**	**10,188**	**169**	**98.32%**	**97.90%**	**1.004**	**2.10%**

The full hospital names can be found in Annex A

The results in Figure 3.6 and Table 3.4 show that over the last 3 years, all centres have performed such that 30-day survival was as predicted or better than predicted, given the alert and alarm control limits, for aggregated outcomes after all surgical procedures in children (description linked to methodology here).

The Congenital Audit also calculates the average PRAiS2 risk adjusted mortality per patient operated upon at each of the 11 centres, as a way to understand the relative complexity of cases at each centre [Table 3.4, last column]. This shows significant variance between centres (Chi-Squared test, P value <0.001), from 1.33% to 2.59%, highlighting different risk profiles of complex CHD and case-mix undertaken by individual centres. It is important to note that surgical activity from two major CHD centres (NHB and GRL) were moved to other centres (GUY and BCH respectively) due to the pandemic crisis.

3.2.2.2 30-Day Survival after 83 Specific Procedures

Survival at 30 days was analysed for 83 major surgical, transcatheter cardiovascular and electrophysiological interventions undertaken to treat congenital heart disease at any age (children and adults analysed separately), excluding minor and non-cardiovascular procedures. 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,[31] which sets out a process for providing assurance that all hospitals provide the expected quality of care. For details, click here.

3.2.2.3 30-Day Aggregate Survival after Congenital Heart Surgery in Adults

All 12 centres that undertook more than 30 operative procedures in 2018/19 to 2020/21 performed such that 30-day survival was as predicted, given the alert and alarm control limits, after all surgical procedures in adults with congenital heart disease.

The outcome results in Table 3.5 and Figure 3.7 show that there were 2302 adult patients operated upon during 2018/21. The overall actual to predicted survival ratio was 1.002, and this year there were approximately 10% fewer deaths than predicted by the STAT mortality model, which predicted 38 deaths, whilst actual deaths were 34.

Figure 3.7: Actual vs Predicted Survival using STAT mortality score methodology for the 12 centres in the UK undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over, 2018/21 [NCHDA data]

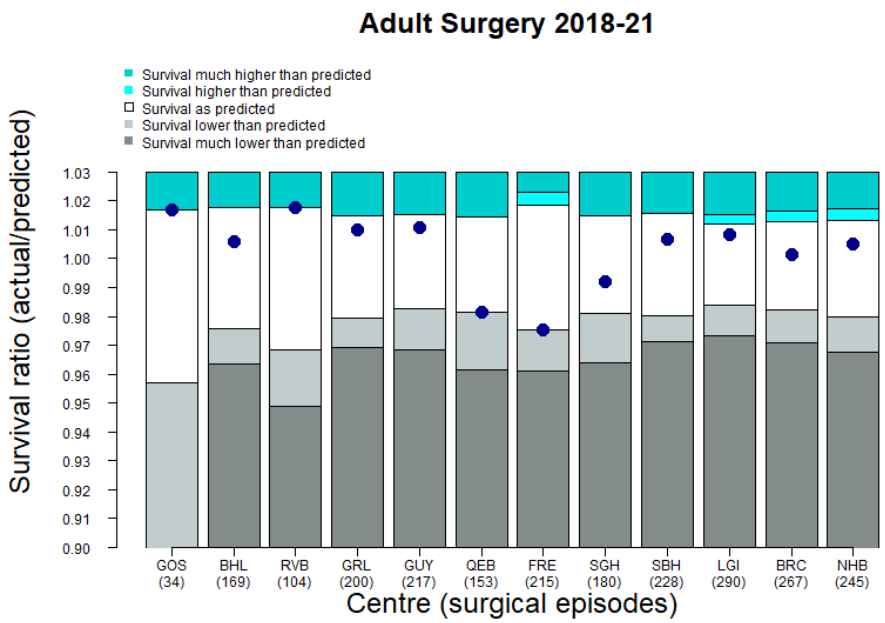


Table 3.5: Actual and Predicted Survival using STAT mortality risk methodology to give the average predicted risk of death per case centres undertaking at least 30 congenital heart surgical procedures in patients aged 16 years and over, 2018/21 [NCHDA data]

Hospital	Surgical Episodes	Survivors	Deaths	Actual Survival	Predicted Survival	Actual/ Predicted	Average Risk per case
GOS	34	34	0	100.00%	98.33%	1.017	1.67%
BHL	169	16*	<3	>98.22%	98.26%	>1.000	1.74%
RVB	104	104	0	100.00%	98.28%	1.0175	1.72%
GRL	200	19*	<3	>98.50%	98.53%	>1.000	1.47%
GUY	217	21*	<3	>98.62%	98.49%	>1.001	1.51%
QEB	153	148	5	96.73%	98.57%	0.9813	1.43%
FRE	213	205	10	95.35%	97.74%	0.9755	2.26%
SGH	180	176	4	97.78%	98.55%	0.9922	1.45%
SBH	228	22*	<3	>98.68%	98.45%	>1.002	1.55%
LGI	290	28*	<3	>98.97%	98.49%	>1.005	1.51%
BRC	267	263	4	98.50%	98.37%	1.0013	1.63%
NHB	245	242	3	98.78%	98.30%	1.0049	1.70%
Overall	**2,302**	**2,268**	**34**	**98.62%**	**98.36%**	**1.0025**	**1.64%**

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.

In comparison with 2017/20, there was a 44% drop in surgical procedures in 2020/21. For the cases performed, the 2018/21 predicted mortality is lower than 2017/20, and actual deaths are fewer than predicted deaths. In addition, there were no centre level outliers for any of the 44 specific surgical procedures analysed for 30-day mortality. This suggests that the outcomes are likely not to be outside the statistically acceptable limits used within the STAT risk-adjustment model.

The audit also calculates the average risk adjusted mortality per patient operated upon at each of the 12 centres [Table 3.5, last column] highlighting variance between centres from 1.43% to 2.26%, demonstrating different risk profiles of complex CHD and case-mix undertaken by individual centres. For instance, Newcastle is known to undertake cardiac transplantation in patients with a background of complex congenital heart disease.

The NCHDA will focus efforts on the development of new QI metrics, long-term outcomes by diagnosis, collaborative initiatives to reduce early morbidity, and patient reported outcome measures (PROMs). The success of these initiatives is partly dependent on securing analytical resources and funding for research outside the audit structure.

3.3 There is some inter-centre variance in rates of post-procedural complications

We recognise that excellent early survival rates supplemented by a wider range of outcome measures help better evaluate the longer-term clinical and health-economic impact following paediatric and adult congenital heart interventions.[32]

In April 2015, the NCHDA introduced separate data fields to capture post-procedural complications following surgery and transcatheter interventions (including electrophysiology), in anticipation of being able to analyse data from three years during the current analytical cycle. In the report last year, we emphasised that measurement of post-procedure complications is challenging. We have made significant progress and aim to have better definitions for this metric allowing consistent data submission and accurate analysis of early morbidities associated to cardiac surgery.

Post-procedure complication rates for children (less than 16 years of age) following 3,384 surgical procedures and 2,724 transcatheter interventions at 11 UK and Republic of Ireland centres during 2018/21 are reported and can be seen in Table 3.6.

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** • **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 least incidence is usually optimal and this is usual dependant on the patient's preoperative 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[32] • 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[33] • 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[34]
Numerator	Count of patients with a coded complication.
Denominator	Countable surgical procedures.
Trend	N/A 5-year aggregate for individual hospitals planned in the future when enough data are accumulated without impact of pandemic.
Variance	Some inter-centre variance is seen in the incidence of each complication. Detailed case-mix and specific procedure adjusted analysis of causation is required in the future to establish best practice for benchmarking and well-defined data variables for complications.

3.3.2 Audit results

The analyses focused on four surgical- and two interventional catheter-related complications and Table 3.6 demonstrates the rate of all six post-procedural complications for 11 paediatric centres (Scottish centres excluded) for 2020/21.

Table 3.6: Rate of all 6 post-procedural complications for 11 paediatric UK & RoI centres for 2020/21 [NCHDA data]

Hospital	ECMO (%)	Renal (%)	Pacemaker (%)	Pleural (%)	Trans-catheter Cx (%)	Cath Device Emb (%)
BCH	2.63	2.61	1.32	2.62	0.81	2.44
BRC	1.54	8.49	0.77	3.86	0.46	0.00
OLS	3.04	0.83	3.59	2.76	0.89	0.67
LGI	0.29	3.50	1.75	1.17	1.78	1.42
GRL	4.14	0.69	1.38	1.38	1.23	0.00
ACH	5.07	4.48	1.49	1.79	0.41	0.00
GUY	0.83	7.73	0.55	1.38	0.00	0.43
GOS	1.54	4.43	0.77	2.12	0.00	0.48
NHB	1.82	2.42	2.42	0.00	0.97	0.97
FRE	8.52	6.25	1.14	0.57	0.69	0.69
SGH	1.33	2.22	1.78	0.89	0.96	0.00
Total	**2.48**	**4.10**	**1.50**	**1.86**	**0.75**	**0.71**

The full hospital names can be found in Annex A

3.3.3 Recommendation

The NCHDA has made significant progress with the development of better definitions to help centres record post-procedural complications, allowing consistent data submission and accurate analysis of early morbidities associated with cardiac surgery. All hospitals should comply with the accurate recording of these complications according to the existing definitions.

3.4 Antenatal diagnosis has improved

About 20–30% of congenital heart defects are severe, defined as being potentially life threatening and requiring surgery within the first year of life.[35,36] 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.[37]

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

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 but further discussion is required to determine whether different realistically achievable targets are needed for specific lesions. Poor antenatal diagnosis rates are associated with limited opportunity to counsel expectant patients and worse outcomes for babies.[38]

With considerable regional variations in diagnostic rates of congenital heart disease before birth, the NCHDA have been working to modify geographical analysis to fit in with contemporary regional boundaries. With the launch of 44 sustainability and transformation partnerships (STP) in NHS England regions, part of NHS England and NHS Improvement's long-term vison to establish integrated care systems (ICS), we have used regional STP boundaries to map PPD rates.[39]

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)** • **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 reduces 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.[37] 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.[38]
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 centre.
Trend	This year we have used regional STP boundaries to map PPD rates for NHS England centres.[39] Ongoing improvement in PPD rates for infants requiring a cardiovascular procedure over the last 10 years across the UK and Republic of Ireland, as well as regional levels in England and Wales. The overall detection is slightly better when compared to 2019/20.
Variance	Table 3.8: While considerable regional variation remains between centres and their diagnostic success rate of CHD in those requiring a procedure in infancy, using STP mapping highlights improvement in PPD detection rates as regional boundaries are better defined.

Whilst different periods of the pandemic and social distancing rules may have affected patient choices, the overall PPD rates remained similar or better in 2020/21 compared with 2019/20. It is important to note that PPD detection rate is determined by the screening hospitals and not by CHD centres.

3.4.2 Audit Results

3.4.2.1 Overall detection of infants requiring a procedure

There was a slight improvement in PPD rates in 2020/21 [Table 3.7 and Figure 3.8]. The detection rate was 52.3% for all infants requiring a procedure in the first year of life [Figure 3.8]. Table 3.8 demonstrates the national variation of antenatal diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2020/21 in the UK and RoI using STP maps for centres in England.

Table 3.7: Percentage of patients undergoing procedures in infancy successfully diagnosed antenatally in the UK and RoI (excluding Scotland) [NCHDA data]

Overall Diagnosis in 2011/12 – 2020/21			
Year	**Overall diagnosis**	**Total**	**Antenatally diagnosed**
2011/12	721	2,209	32.6
2012/13	723	2,149	33.6
2013/14	804	2,105	38.2
2014/15	814	2,046	39.8
2015/16	863	2,063	41.8
2016/17	908	2,118	42.9
2017/18	1,123	2,164	51.9
2018/19	1,099	2,138	51.4
2019/20	963	1,935	49.8
2020/21	910	1,740	52.3

Note: Activity reduction compared to previous year publications due to the exclusion of Scotland data

Figure 3.8: Percentage of patients undergoing procedures in infancy successfully diagnosed antenatally in the UK and RoI (excluding Scotland) [NCHDA data]

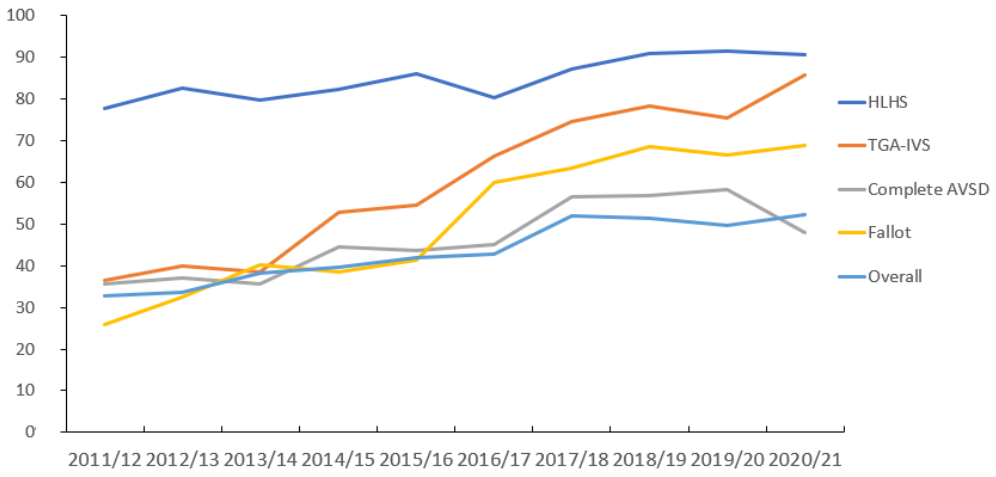


Table 3.8: Regional (Sustainability Transformation and Partnerships (STP)) and national variation in antenatal diagnosis rates for infants who underwent a procedure in the first year of life for any cardiac malformation 2020/21 in the UK and RoI (data from hospitals in Scotland not included) [NCHDA data]

Overall Diagnosis in 2020–21			
STP	**Overall diagnosis**	**Total**	**% Antenatally diagnosed**
Channel Islands	<3	7	<42.9%
England	738	1,408	52.4%
Isle of Man	<3	<3	100.0%
Northern Ireland	35	63	55.6%
Republic of Ireland	81	166	48.8%
Wales	43	72	59.7%
QE1. Healthier Lancashire and South Cumbria	24	41	58.5%
QF7. South Yorkshire and Bassetlaw	22	49	44.9%
QGH. Herefordshire and Worcestershire	11	13	84.6%
QH8. Mid and South Essex	12	26	46.2%
QHG. Bedfordshire, Luton and Milton Keynes	22	37	59.5%
QHL. Birmingham and Solihull	19	42	45.2%
QHM. Cumbria and North East	46	86	53.5%
QJ2. Joined Up Care Derbyshire	8	14	57.1%
QJG. Suffolk and North East Essex	11	22	50.0%
QJK. Devon	9	16	56.3%
QJM. Lincolnshire	8	22	36.4%
QK1. Leicester, Leicestershire and Rutland	12	24	50.0%
QKK. Our Healthier South East London	17	35	48.6%
QKS. Kent and Medway	23	38	60.5%
QM7. Hertfordshire and West Essex	14	26	53.8%
QMF. East London Health and Care Partnership	40	77	51.9%
QMJ. North London Partners in Health and Care	21	47	44.7%
QMM. Norfolk and Waveney Health and Care Partnership	14	29	48.3%
QNC. Staffordshire and Stoke on Trent	15	25	60.0%
QNQ. Frimley Health and Care ICS	12	20	60.0%
QNX. Sussex and East Surrey Health and Care Partnership	18	33	54.5%
QOC. Shropshire and Telford and Wrekin	<3	5	<60.0%
QOP. Greater Manchester Health and Social Care Partnership	28	59	47.5%
QOQ. Humber, Coast and Vale	24	38	63.2%
QOX. Bath and North East Somerset, Swindon and Wiltshire	8	13	61.5%
QPM. Northamptonshire	8	20	40.0%
QR1. Gloucestershire	5	7	71.4%
QRL. Hampshire and the Isle of Wight	22	34	64.7%
QRV. North West London Health and Care Partnership	40	61	65.6%
QSL. Somerset	6	10	60.0%
QT1. Nottingham and Nottinghamshire Health and Care	8	16	50.0%
QT6. Cornwall and the Isles of Scilly Health and Social Care Partnership	3	14	21.4%
QU9. Buckinghamshire, Oxfordshire and Berkshire West	19	44	43.2%
QUA. The Black Country and West Birmingham	22	49	44.9%
QUE. Cambridgeshire and Peterborough	10	21	47.6%
QUY. Bristol, North Somerset and South Gloucestershire	16	23	69.6%
QVV. Dorset	12	23	52.2%
QWE. South West London Health and Care Partnership	31	47	66.0%
QWO. West Yorkshire and Harrogate (Health and Care Partnership)	33	81	40.7%
QWU. Coventry and Warwickshire	13	28	46.4%
QXU. Surrey Heartlands Health and Care Partnership	16	24	66.7%
QYG. Cheshire and Merseyside	35	69	50.7%
North Wales	8	13	61.5%
South Wales			
7A2	6	7	85.7%
7A3	9	13	69.2%
7A4	6	9	66.7%
7A5	6	13	46.2%
7A6	7	15	46.7%
7A7	<3	<3	<100.0%
Oversea	8	16	50.0%
Unknown	<3	7	<42.9%
Total	**910**	**1,740**	**52.3%**

The funnel plots and STP maps below [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 only continuing pregnancies are included of babies who have required an intervention in infancy.

Figure 3.9: Overall PPD rates by region for (a) 2018/21 and (b) 1-year overall PPD rates by region, 2020/21 [NCHDA data]

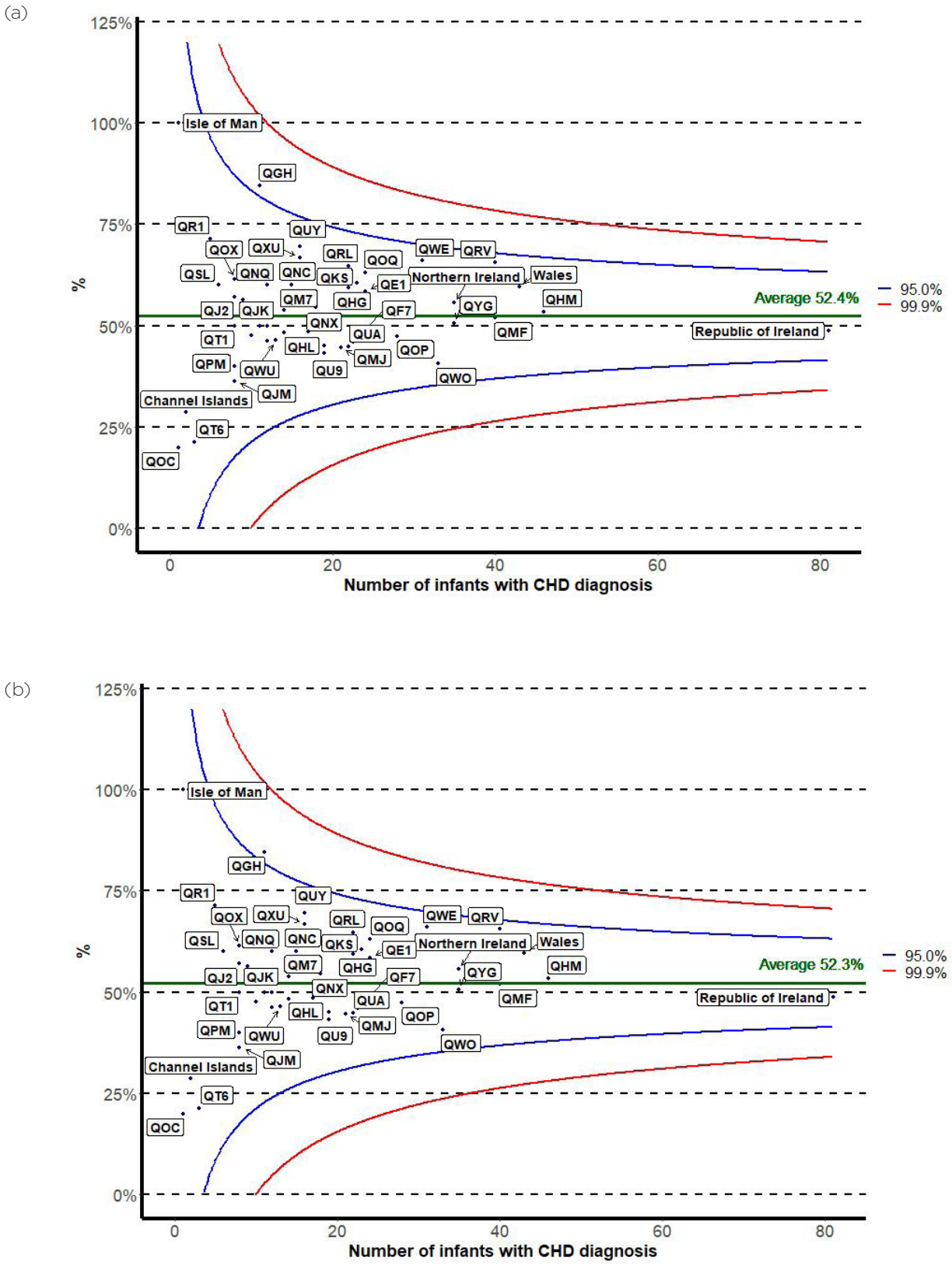


Figure 3.10: Overall PPD rates by STP for (a) 2018/21 and (b) 2020/21. The map demonstrates better detection rates across England centres for 2020/21 compared to the average detection over the last 3 years (2018 – 2021) [NCHDA]

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

- Agreement on which pregnancies undergo sonographic evaluation
- Mandatory training of the sonographers
- Storage of specific cardiac views to allow internal and external review to encourage a learning process.

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

3.4.2.2 Detection rates for individual cardiac malformations

Table 3.9 shows that the detection rate of four individual cardiac lesions remains at a continued high rate. For hypoplastic left heart syndrome, this has risen from about 78% ten years ago to over 90% this year.

The improvement in TGA-IVS is particularly impressive and due to the incorporation of the 3-vessel and trachea (3VT) view into the fetal anomaly screening programme with over 85% pick-up rate this year.

Table 3.9: 10-year detection rates for HLHS, TGA-IVS, complete AVSD and tetralogy of Fallot antenatally diagnosed for patients who underwent a procedure within 12 months of birth (2011/12 – 2020/21) in the UK and Republic of Ireland (data from hospitals in Scotland excluded) [NCHDA]

Year	HLHS	TGA-IVS	Complete AVSD	Fallot	Overall
2011/12	77.9	36.6	35.5	25.9	32.6
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	91.7	75.5	58.4	66.7	49.8
2020/21	90.6	85.7	47.9	68.8	52.3

10-year tables for diagnostic rates and funnel plots depicting the PPD rates by region for the three years 2018/19 to 2020/21 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.

3.5 Data Quality Indicator (DQI)

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 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 Standards.
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.[40] https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-Heart-Disease-Standards-Level-1-Specialist-Surgical-Centres-Adult.pdf.[25]
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: • 12 centres score 98% or more • 2 centres score between 95 – <98% • 1 centres 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. Variance may also be due to inadequate, centre level, Database staff (Database 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.[25]

Table 3.10 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 3.10: Overall DQI for all centres submitted to NCHDA for 3 years, 2018/19 – 2020/21 [NCHDA data]

	Code	2018–19	2019–20	2020–21	Actual Number of Whole Time Equivalent (WTE) Data Managers for 2020–21)	NHSE Standards 2016 Requirement
Paediatric/Mixed Practice Hospitals						
Birmingham Children's Hospital	BCH	99	99	99.5	1	2 posts
Bristol Royal Children's Hospital	BRC	99.5	99.25	99.5	2.35	3 posts mixed practice
Dublin, Our Lady's Hospital	OLS	99	99	98.5	3	2 posts paeds only
Leeds General Infirmary	LGI	98.25	99	99	2	3 posts mixed practice
Leicester Glenfield Hospital	GRL	94.75	94.75	94.5	1.5	3 posts mixed practice
Liverpool Alder Hey Childrens Hospital	ACH	98.5	98.5	99.5	1.25	2 posts
London Evelina Childrens Hospital	GUY	99.4	97.75	98.75	3	3 posts mixed practice
London Great Ormond Street	GOS	93	97.75	98.5	1	1 post paeds only within a team of 5 in information department
London Harley Street Clinic	HSC	**	**	**	no information	
London Royal Brompton & Harefield	NHB	87.5	95.75	98	2	3 posts mixed practice
Newcastle Freeman	FRE	99	99.75	99.8	1	3 posts mixed practice
Southampton Wessex Cardiothoracic Centre	SGH	98.75	98.25	98.75	1.5	3 posts mixed practice
Adult only Hospitals						
Belfast Royal Victoria	RVB	96	96.75	98	0.5	1 post
Birmingham Queen Elizabeth Hospital	QEB	87.25	95.25	97	1	1 post
Liverpool Heart & Chest Hospital	BHL	93.5	94.75	98.75	1	1 post
London University College/ St Bartholomew's	UCL/ SBH	96.6	98	97.5	1	1 post
Manchester Royal Infirmary	MRI	***	***	***	n/a	

* ACHD only ** No data submitted *** Service transferred **** New Service

<90 90 to <95 95 to <98 >=98

Note: Data from hospitals in Scotland have been excluded from each year.

4 Future direction

Over the next year, the NCHDA audit will have the following aims:

- Continue monitoring the impact of the COVID-19 pandemic on services/models of practice
- Encourage the use of the new online tools to improve data quality and to allow hospitals to see their contemporary performance
- Work to develop new ways of reporting data, e.g. Mapping and Dash Boards with improvements in data quality
- Develop advanced regional reporting at STP/ICS level
- Revise/clarify definitions to improve data quality and completeness through its Working Group
- Link with other datasets to establish new QI metrics for more comprehensive clinical pathways
- Recalibrate the PRAiS risk model and review the criteria for the relevant variables

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This report is available online here.

7 Annex A: List of codes for participating centres 2020/21

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