NCAP

NATIONAL CARDIAC AUDIT PROGRAMME

NICOR

National Congenital Heart Disease Audit (NCHDA)

2024 Summary Report

(2020/21 – 2022/23)

Congenital heart disease - Report at a glance

2022/23 data unless otherwise stated.

11,407 congenital heart disease (CHD) procedures on children and adults

3% increase in the overall number of procedures compared to 2021/22

9% fewer procedures than in 2019/20 prior to the COVID-19 pandemic

5% reduction in surgical procedures on children (**16%** fall since 2019/20)

98% survival rate 30 days after paediatric cardiac surgery continued to be high

1.6% overall 30-day mortality rate for both children and adults is lower than previous year and better than expected based on predicted risk

54% antenatal diagnosis for all infants requiring a procedure in the first year of life is a slight improvement

There is considerable variability in antenatal detection rates for these patients within the UK

Complication rates following a procedure for under-16 CHD patients varied between hospitals.

Recommendations

1. Hospitals undertaking antenatal screening to diagnose conditions requiring intervention in the first year should improve their success rates by working with congenital heart disease (CHD) networks to review staffing, infrastructure, education and training.

2. All hospitals should consistently enter data in line with the new definitions of post-procedure complications released in 2023 for implementation in April 2024.

Introduction

The National Congenital Heart Disease Audit (NCHDA) is part of the National Cardiac Audit Programme (NCAP) which is run by the National Institute for Cardiovascular Outcomes Research (NICOR).

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 one in 100 births are affected by CHD and it is the main cause of infant mortality.[1] 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] 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]

This report focuses on the activity and trends in the treatment of paediatric and adult patients with congenital heart disease (CHD) in the UK and Ireland (other than Scotland which now has its own Scottish Cardiac Audit Programme). It compares performance against several quality improvement (QI) metrics derived from national and/or international standards and guidelines. The goal of CHD services is to make a diagnosis 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.

This report is of value to a wide range of stakeholders but importantly it allows patients and their relatives to better understand CHD care and its outcomes in the UK. **The slides in the report are interactive so you can select and explore the data that interest you.** Additional information on the audit, including definitions and methodology, is available from the National Institute for Cardiovascular Research (NICOR) website .

The audit relies on the active contribution of participating hospitals. Detailed information about more than 11,400 procedures has been diligently entered by local clinical and audit teams, queried and cleaned before analysis is undertaken by the NICOR team. We are very grateful to all these staff for their contributions. We will continue to work closely with hospitals, patients and other stakeholders to improve the quality of audit data and how these are used to improve the delivery of high quality CHD care in the UK.

The NICOR NCHDA audit team

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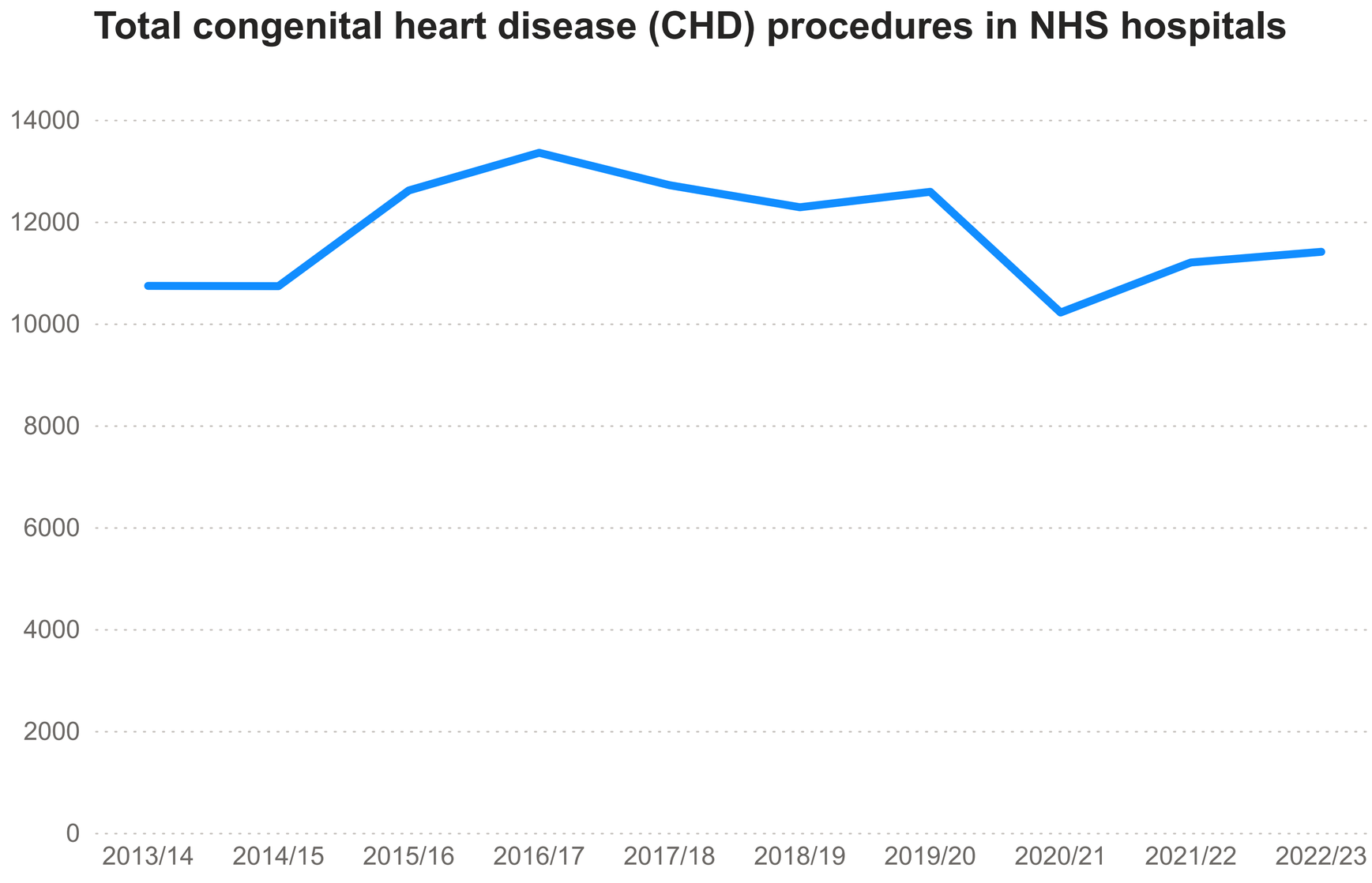
The total number of procedures for patients with congenital heart disease remains below the pre-pandemic level

In 2022/23, the audit recorded 11,407 congenital heart disease (CHD) submissions in children and adults.

This total is 2% higher than in 2021/22 but remains 9% below the 2019/20 figure, prior to the COVID-19 pandemic.

Note: Data from a private centre (Spire Bristol Hospital) were NOT included.



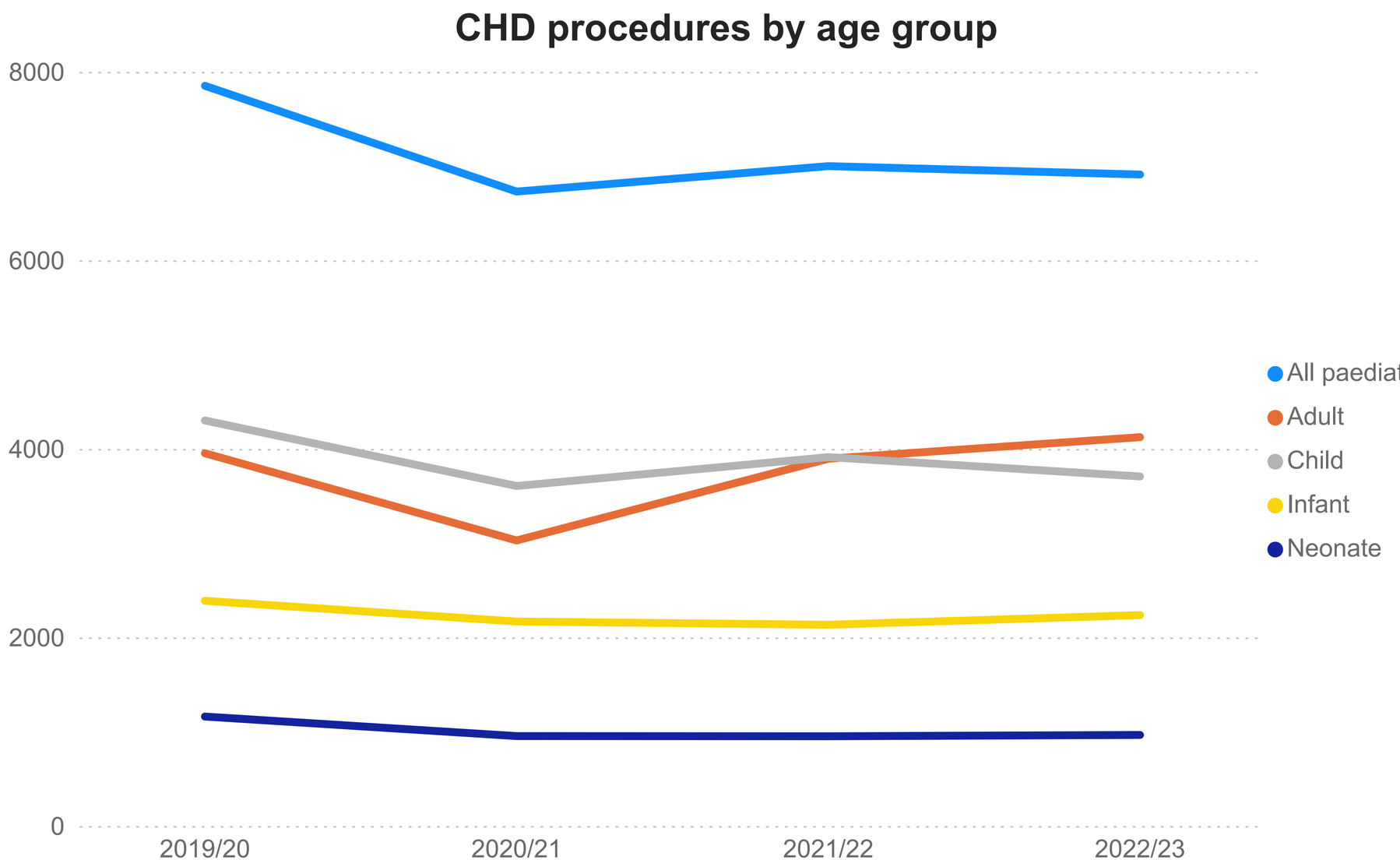
While the number of cases for most age groups is below the pre-pandemic level, the number of adult cases has slightly increased since 2019/20

The number of countable procedures in adults (16 years and above) slightly increased above the 2019/20 level prior to the COVID-19 pandemic.

The number of procedures for paediatric groups (neonatal, infant and child) all remain below pre-pandemic levels.

A number of factors may be driving the slight reductions in paediatric cases:

- Changes to the number of patients requiring treatment
- Shifts in the mix of cases by type, risk and other factors
- Use of different treatment strategies (e.g. undertaking more complex operations earlier rather than having an initial simpler procedure followed by another later)
- The impact of developments in paediatric interventional practice (e.g. percutaneous balloon valvuloplasty).



The fall in overall activity mostly results from a drop in surgical procedures

Surgical procedure numbers were falling slightly prior to the pandemic but the numbers performed in 2022/23 were 14% lower than in 2019/20.

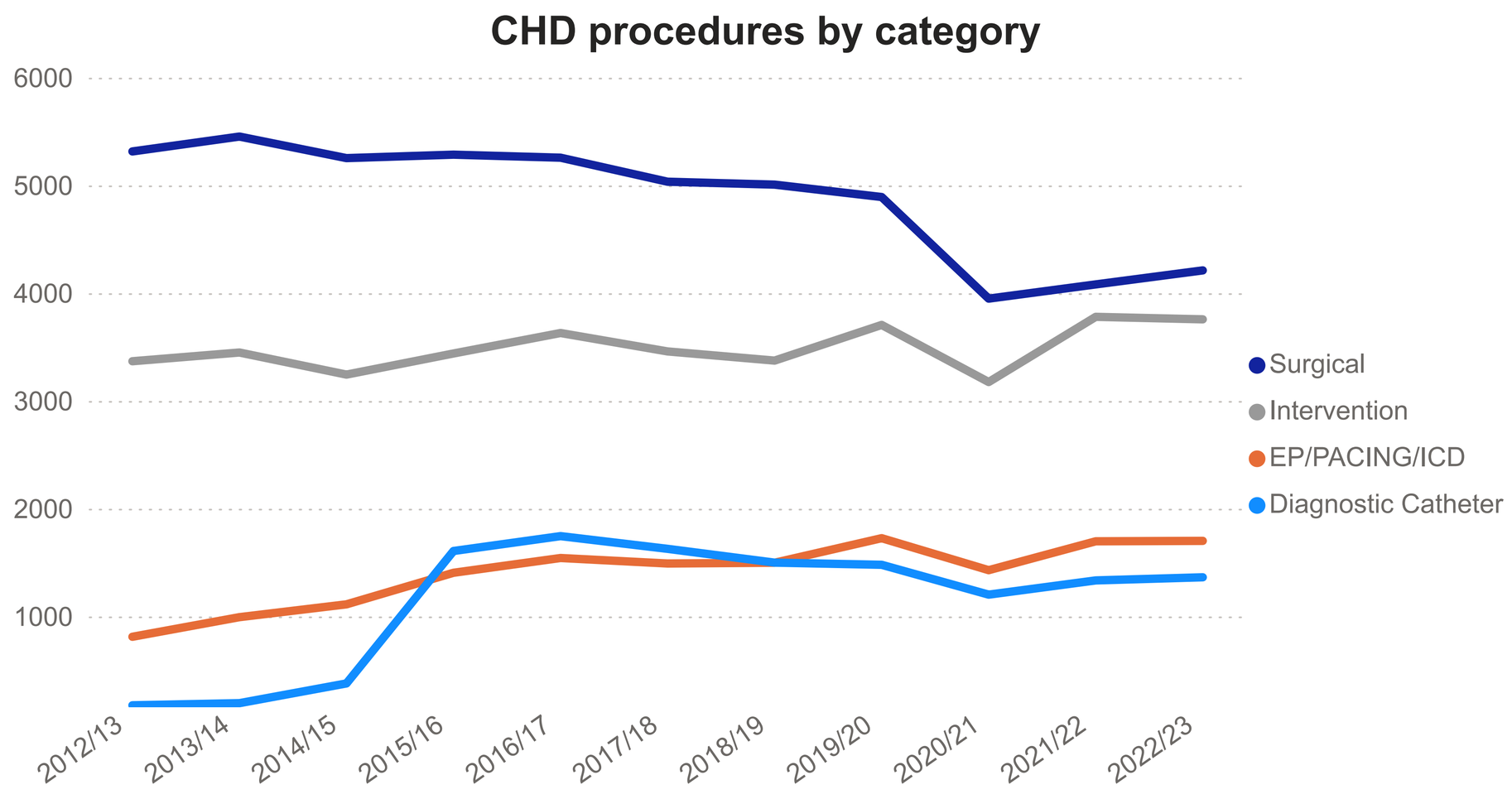
Interventional (catheter-based) procedures were 4% higher than the pre-pandemic level.

Procedures involving electrophysiology (EP) and device implantation, either pacemakers or implantable cardioverter defibrillators (ICDs), were broadly the same in number to 2019/20.

The changes seen may reflect a number of different factors including:

- Patient requirements and case mix
- Infrastructure challenges following the pandemic (e.g. ICU bed availability, staffing issues)
- Changing treatment strategies

Note: Not all hospitals reported data on certain procedures (e.g. diagnostic catheters) from 2012/13



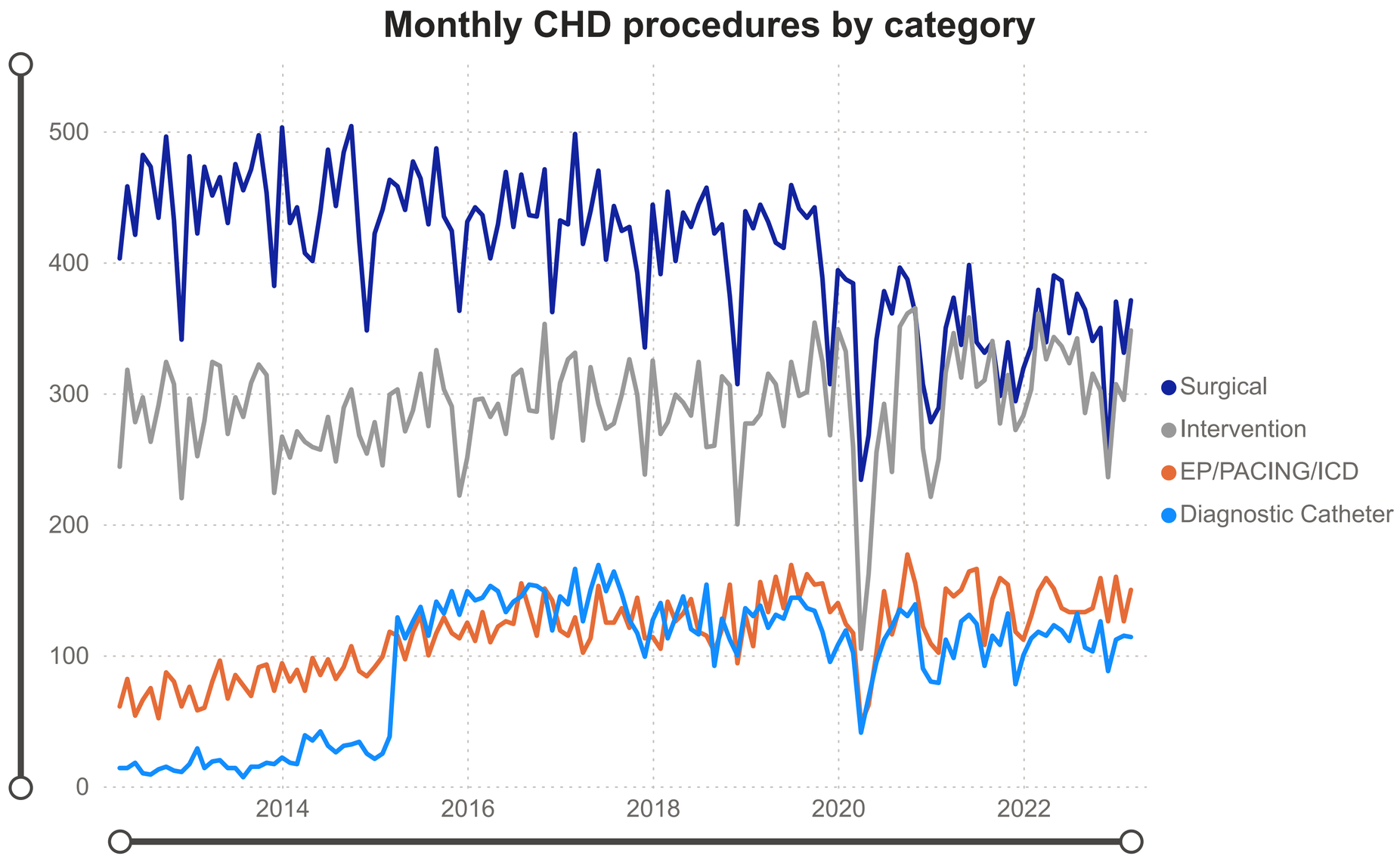
Monthly activity data highlights the on-going impact of the COVID-19 pandemic, especially for surgical procedures

Monthly data highlights the substantial falls in cases during the first two waves of the COVID-19 pandemic in 2020/21.

The impact of the pandemic is seen across all procedures, though activity has been restored for:

- interventional procedures
- electrophysiology (EP) and device implantation (pacemakers and implantable cardioverter defibrillators, ICDs).

The volume of surgical and diagnostic catheter procedures both remain below pre-pandemic levels.



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The fall in overall activity mostly results from a drop in surgical procedures

Surgical procedures include patients requiring:

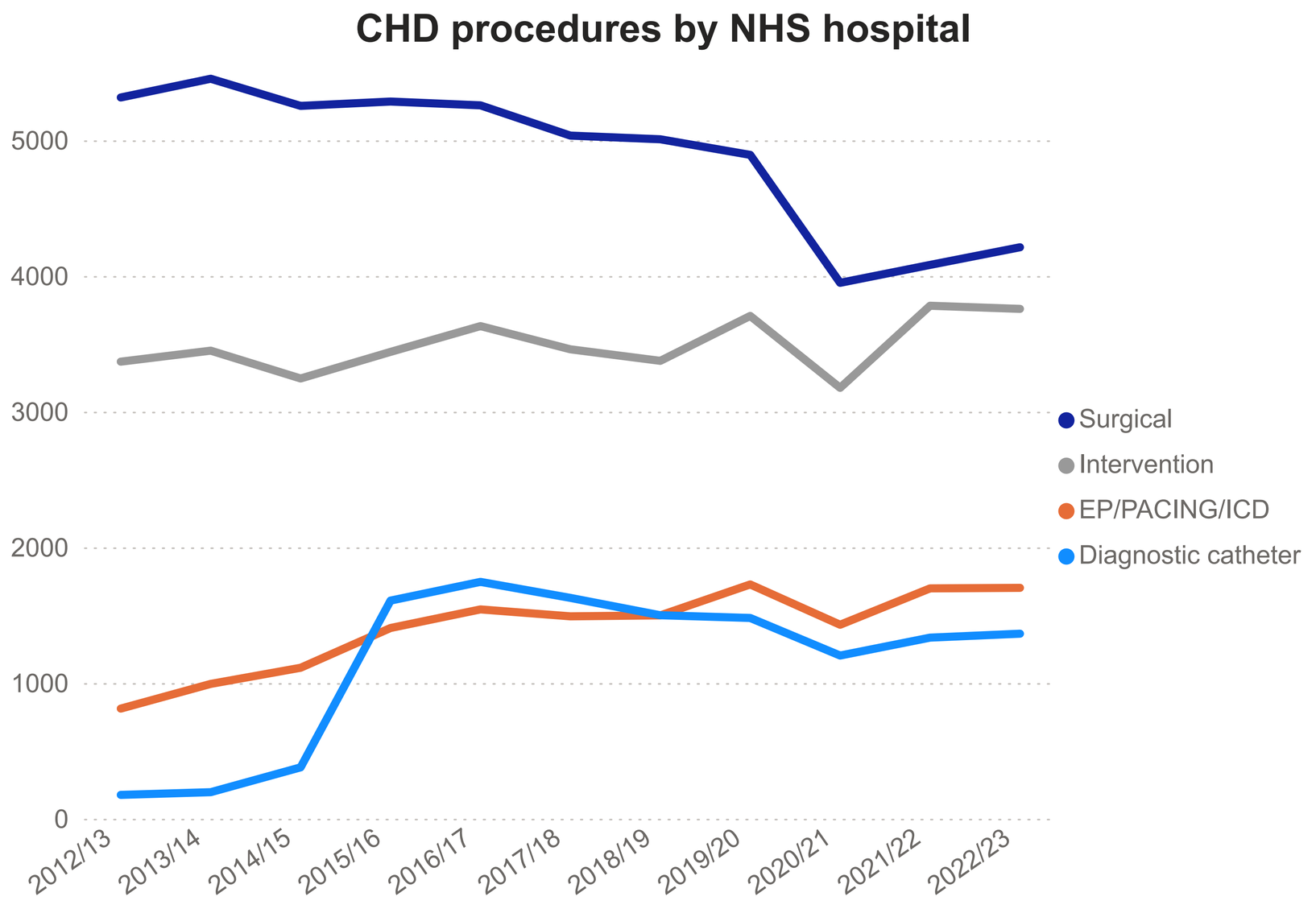
- Bypass
- Non-bypass including electrophysiology (EP) procedures undertaken by surgeons
- Primary ECMO (Extracorporeal Membranous Oxygenation) when this procedure is undertaken in isolation and not as a support operation after another congenital heart procedure (these are considered post-procedural complications).
- Lung Transplant
- Ventricular Assist Devices (VAD)
- Hybrid procedures (those with a combination of surgical and transluminal catheter interventions undertaken at the same time in the operating theatre).

In 2023, the Royal Brompton Hospital, London (NHB) and Evelina London Children's Hospital, London (GUY) - merged into Guy's and St. Thomas' NHS Foundation Trust (GSTT). All CHD procedural activity for those hospitals has been reported under GUY.

Selecting a hospital below shows the number of procedures performed over time.

Hospital

All



One hospital performed over 2,000 procedures in 2022/23 while nine undertook fewer than 100

11,036	4212	3758	1702	1364	⬆1%
Total	**Surgical**	**Intervention**	**EP/PACING/ICD**	**Diagnostic Catheter**	**Change on previous year**

Financial Year

2022

Hospital

All

Age Group

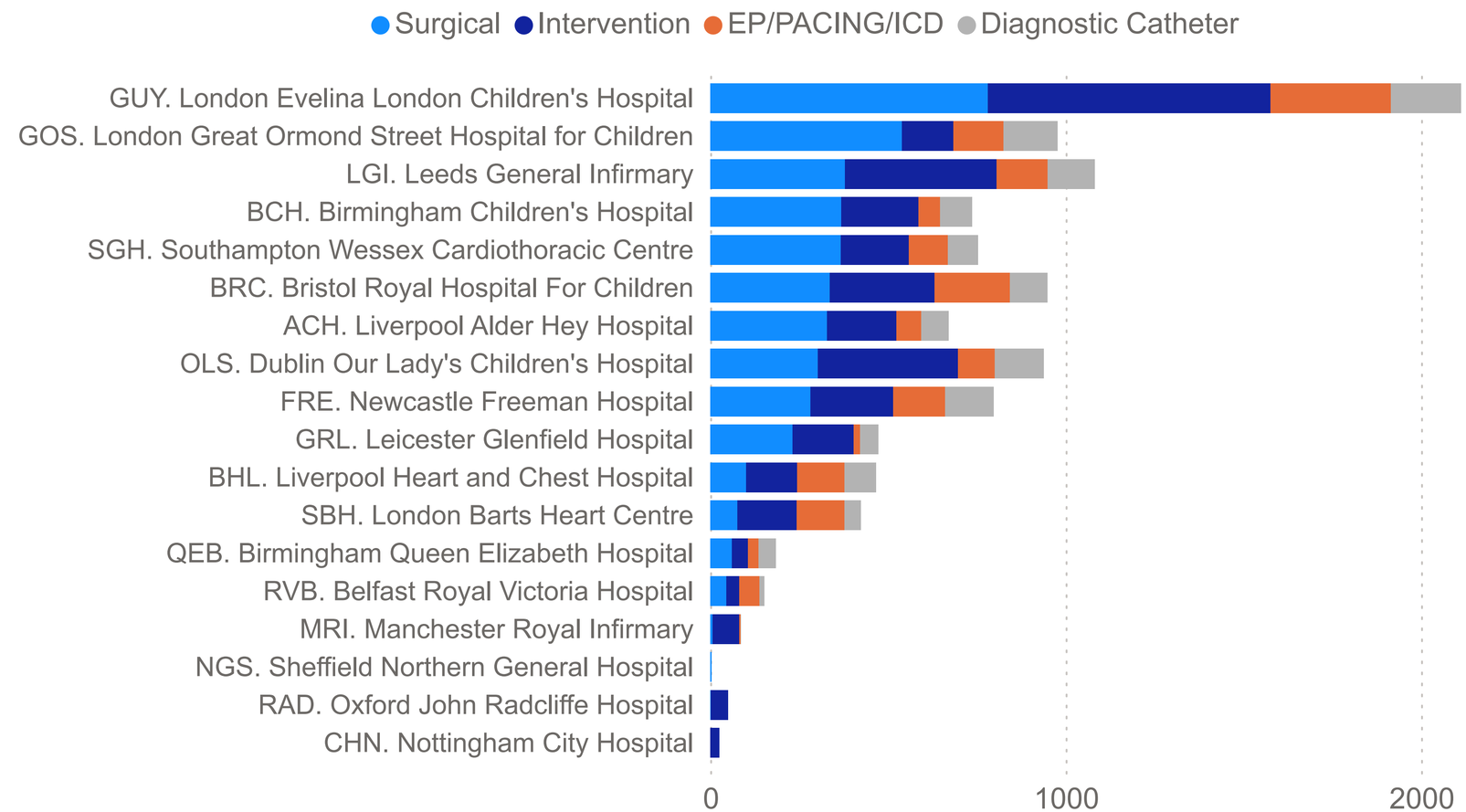
All

Procedure Type

All

Note: Some hospitals with small volumes may perform fewer than three cases in some categories. To comply with small number suppression, these have been deleted and the totals for these centres will therefore be slightly lower than their actual activity. 'x' in the totals means a number between zero and nine has been deleted.

CHD procedures by category by hospital

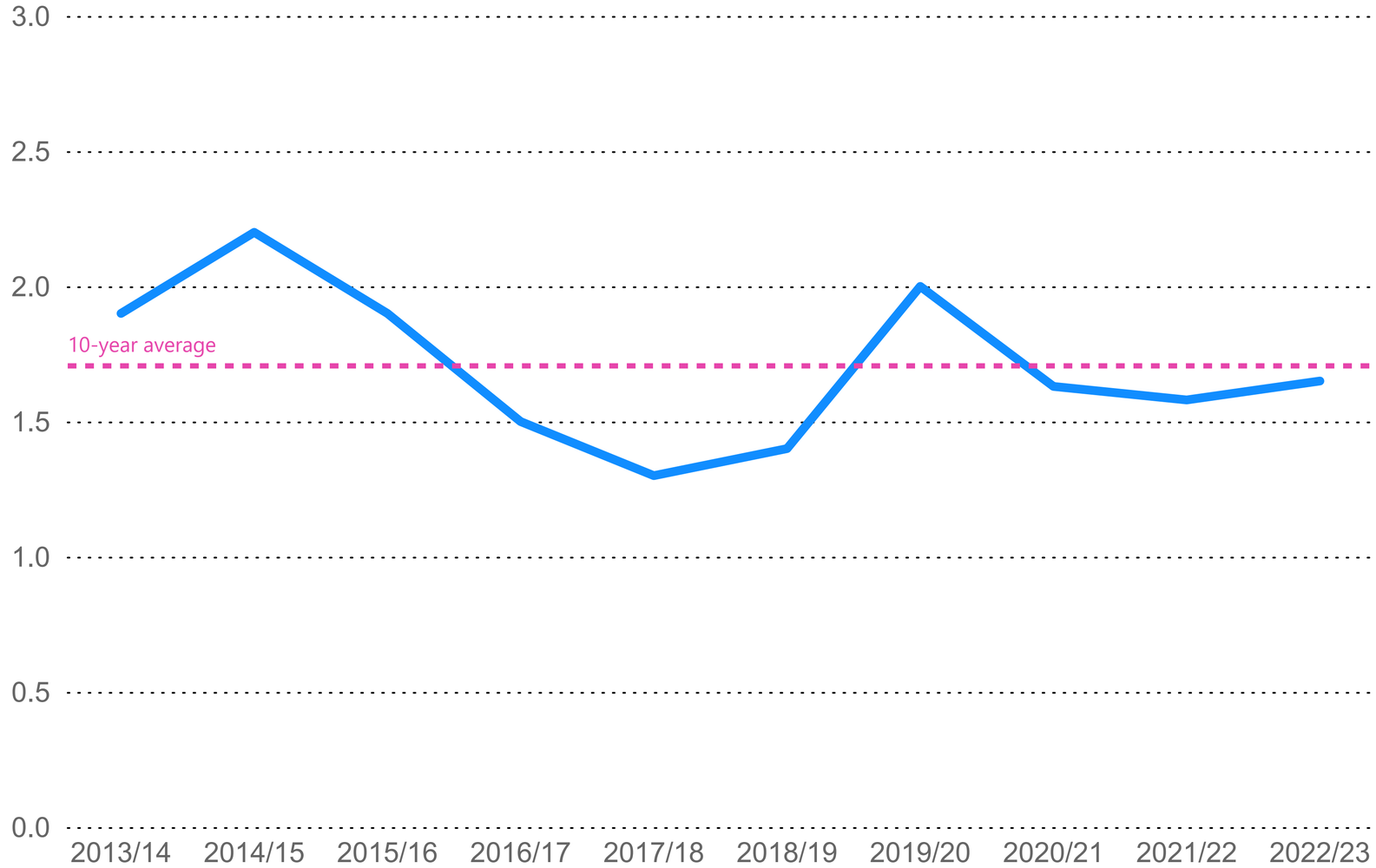


Mortality remains low for cases involving children with congenital heart disease

In 2022/23, the overall unadjusted 30-day mortality remained low at 1.65%.

This is based on 8,841 surgical procedures undertaken in children under 16 years old.

Unadjusted 30-day surgical mortality (%) in children under 16 years



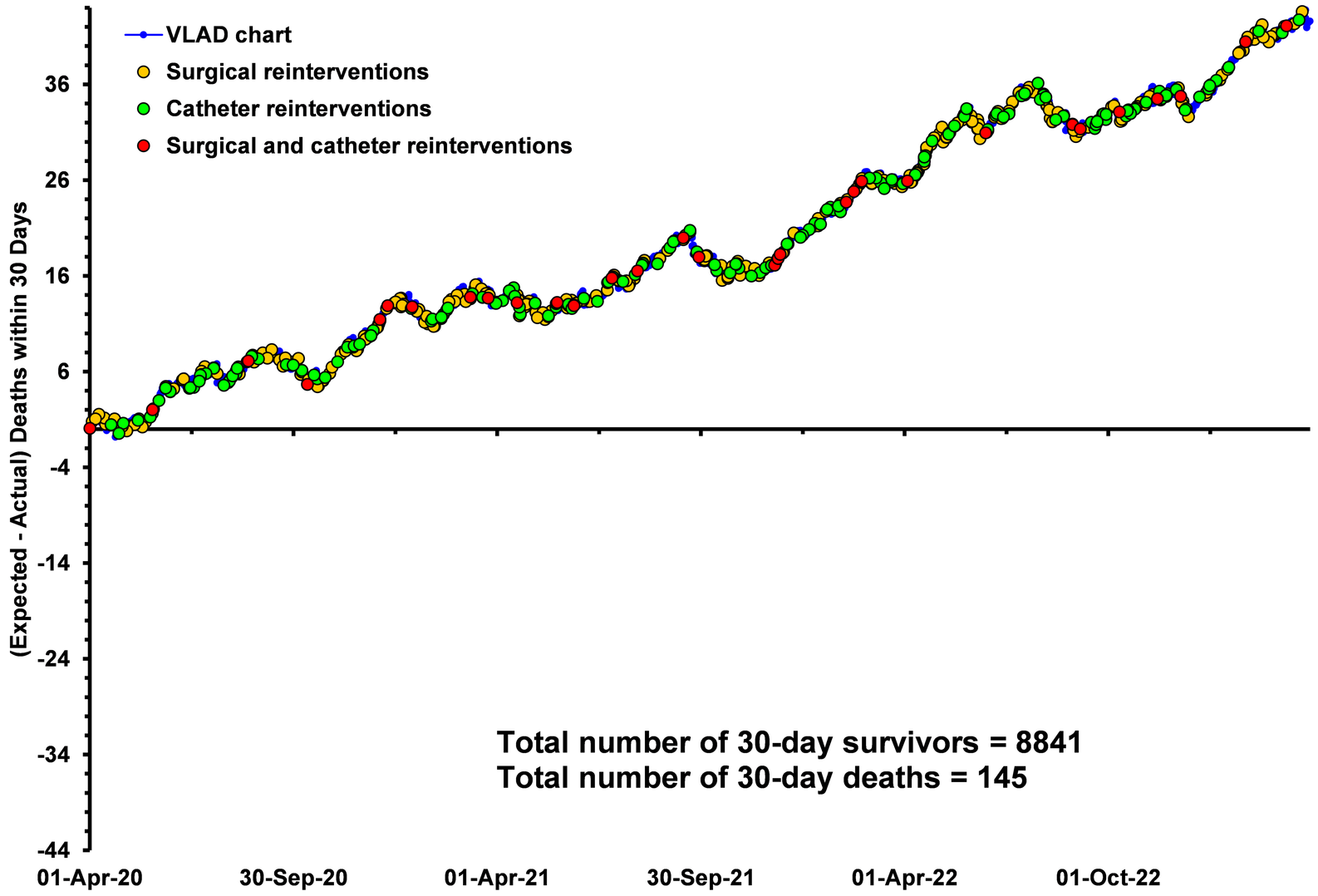
Risk-adjusted mortality based on VLAD charts shows that the outcomes for children with congenital heart disease are better than predicted

Specialist centres monitor the outcomes of their own services using Variable Life Adjusted Display (VLAD) plots.

These show the predicted number of deaths minus the actual number at 30 days post-surgery, along with the number of re-interventions.

Over the three years from April 2020 to March 2023, there was a continuing improving trend in outcomes compared with the predictions from the PRAiS2 risk model.

This underlines how surgical teams continue to deliver high quality outcomes for children undergoing CHD procedures.



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Overall risk-adjusted three-year results showed better than predicted survival rates

To compare mortality outcomes across centres, it is necessary to adjust for the relative complexity of the cases that are being undertaking.

This is done using the PRAiS2 model which reports the ratio of the actual versus the predicted survival of patients (calculated over the 8,986 paediatric patients operated upon during the 3-year 2020/23 period).

Over the last three years, t**he overall survival ratio of 98.4% was slightly higher than the survival predicted by the PRAiS2 model (97.9%)**.

In addition, all centres had survival rates that were equal to or better than predicted.

There were noticeable variance between centres in the average predicted mortality per case, from 1.8% for Birmingham to 2.4% for Bristol.

This highlights the different risk profiles of complex congenital heart disease and case-mix undertaken by individual centres.

A description of the PRAiS2 model can be found here along with the relevant alert and alarm control limits to warn where performance may be of concern.

Actual and predicted average survival rates for paediatric CHD cases using PRAiS2 model (2020/23)

Hospital	Code	Surgical Episodes	Survivors	Deaths	Actual Survival	Predic Surviv
London Great Ormond Street Hospital for Children	GOS	1429	1420	9	99.4%	98
Bristol Royal Hospital For Children	BRC	675	666	9	98.7%	97
Southampton Wessex Cardiothoracic Centre	SGH	705	698	7	99.0%	97
Leicester Glenfield Hospital	GRL	504	499	5	99.0%	98
Liverpool Alder Hey Hospital	ACH	912	895	17	98.1%	97
Leeds General Infirmary	LGI	800	785	15	98.1%	97
London Evelina London Children's Hospital	GUY/GSTT	1524	1499	25	98.4%	98
Birmingham Children's Hospital	BCH	1062	1038	24	97.7%	97
Dublin Our Lady's Children's Hospital	OLS	897	876	21	97.7%	97
Newcastle Freeman Hospital	FRE	478	465	13	97.3%	97
Total		8986	8841	145	98.4%	97

Survival rates for children undergoing congenital heart disease procedures are as, or better than, predicted

The results from the PRAiS2 risk-adjustment model can also identify 'outliers' by showing whether the survival outcomes achieved were as predicted, much higher or much lower.

For the 3-year period 2020/23:

- **seven centres performed as predicted**
- **two centres achieved results that were higher than expected (Bristol Royal Hospital for Children and Southampton Wessex Cardiothoracic Centre)**
- **London Great Ormond Street Hospital for Children had survival rates that were much higher than expected.**

Key:

FRE	Freeman Road Hospital, Newcastle
GRL	Glenfield Hospital, Leicester
BRC	Bristol Royal Hospital for Children
SGH	Southampton General Hospital
OLS	Our Lady's Children's Hospital, Dublin
ACH	Alder Hey Children's Hospital, Liverpool
LGI	Leeds General Infirmary
GSTT	Evelina London Children's Hospital
BCH	Birmingham Children's Hospital
GOS	Great Ormond Street Hospital for Children

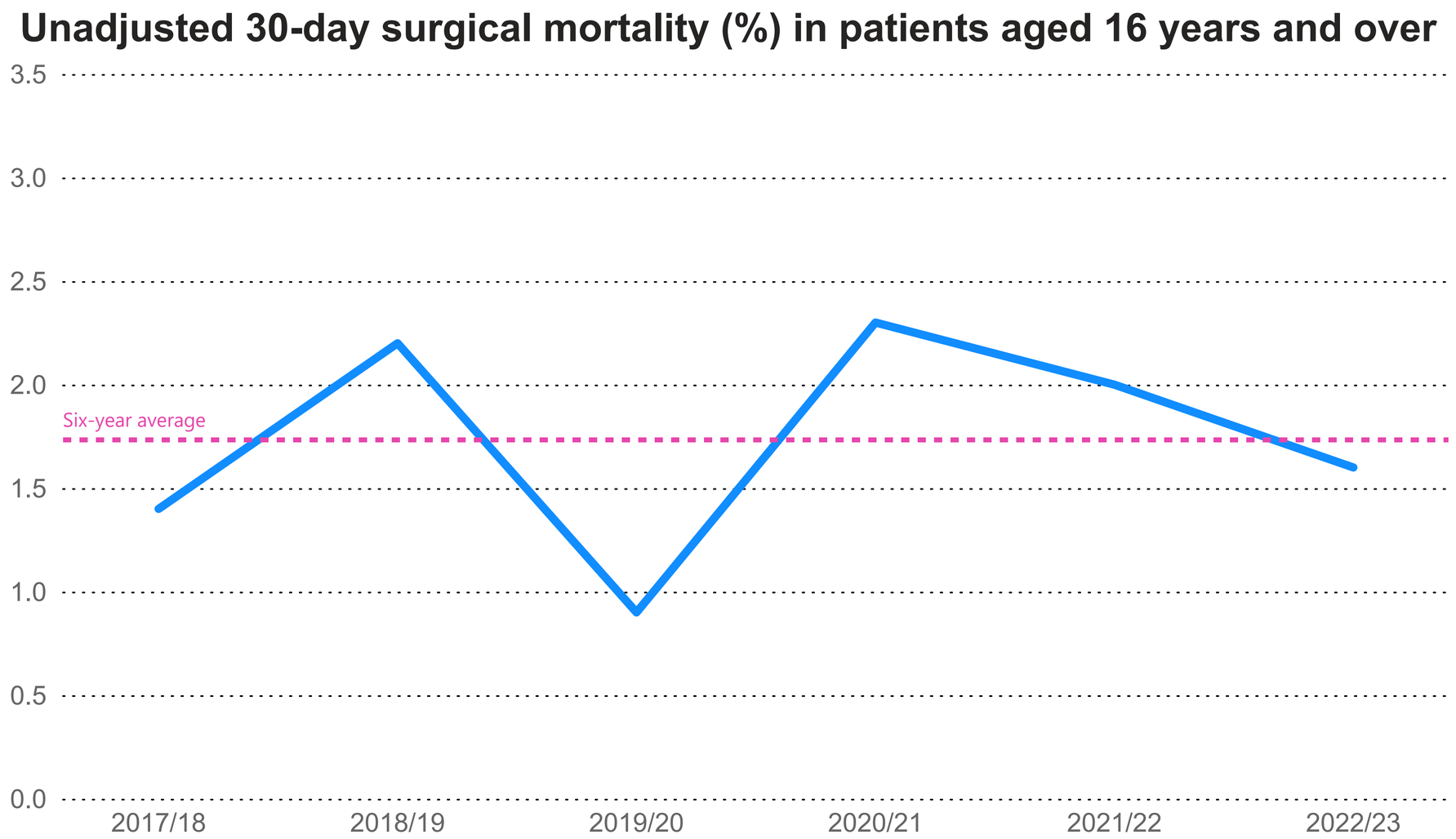
Average survival rates relative to prediction for paediatric CHD cases using PRAiS2 model (2020/23)

The overall 30-day surgical mortality in adults with congenital heart lesions remains low

The overall unadjusted mortality rate for patients aged 16 years and over remains low at 1.61% (30 days after the date of operation).

This is based on a total of 869 surgical procedures.

Note: Society of Thoracic Surgeons–European Association for Cardio-thoracic Surgery (STAT) mortality score was implemented for use as an aggregated assessment of 30-day survival for adults with congenital heart disease operated upon in the UK since 2017/18.



Surgical survival rates for patients with congenital heart disease aged 16 years or more are in line with predicted levels, even with very different case mixes

From 2020 to 2023, a total of 2,080 patients aged 16 years or over underwent congenital heart disease (CHD) surgical procedures.

To compare mortality outcomes across individual centres, it is necessary to adjust for the relative complexity of the cases that are being undertaking. This is done using the STAT risk model.

The overall risk-adjusted survival rate in 2022/23 was 98.1%, slightly higher than the prediction of 97.7%.

The average risk-adjusted predicted mortality across all patients at each of the 10 centres varied between 1.43% and 2.76%.

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).

Even with these very different case mixes, the results demonstrate that survival after surgery at each centre was within the expected limits (all the centres undertook more than 30 adult surgical procedures).

A description of the STAT model can be found here along with the relevant alert and alarm control limits to warn where performance may be of concern.

Actual and predicted average survival rates for adult CHD cases using STAT model (2020/23)

Hospital	Surgical Episodes	Survivors	Deaths	Actual Survival	Predicted S
Leeds General Infirmary	247	247	0	100.0%	98.2%
Belfast Royal Victoria Hospital	99	98	1	99.0%	98.4%
Bristol Royal Hospital For Children	263	259	4	98.5%	98.2%
Liverpool Heart and Chest Hospital	237	234	3	98.7%	98.6%
London Evelina London Children's Hospital	415	408	7	98.3%	98.2%
Birmingham Queen Elizabeth Hospital	113	111	2	98.2%	98.3%
Leicester Glenfield Hospital	113	111	2	98.2%	98.6%
Southampton Wessex Cardiothoracic Centre	206	202	4	98.1%	98.5%
London Barts Heart Centre	190	183	7	96.3%	98.2%
Newcastle Freeman Hospital	197	187	10	94.9%	97.2%
Total	2080	2040	40	98.1%	98.2%

All hospitals achieved survival outcomes as predicted or better for adults undergoing congenital heart disease procedures

The results from the STAT risk-adjustment model can also identify 'outliers' by showing whether the overall survival outcomes for each hospital were as predicted or were much higher or much lower.

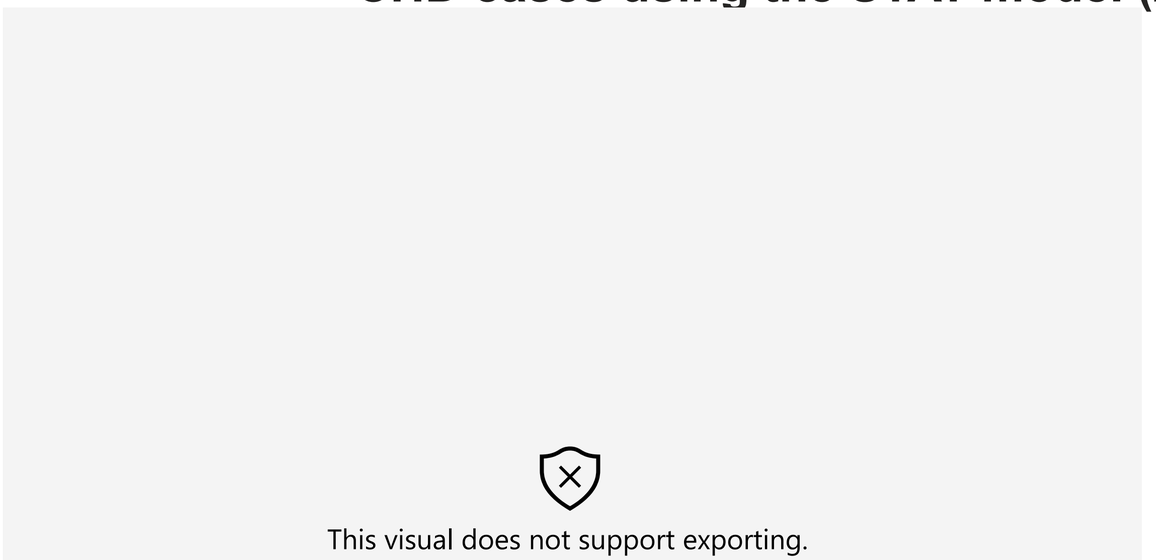
For the 3-year period 2020/23, 10 centres performed as predicted and Leeds General Infirmary achieved outcomes higher than expected.

In addition, individual analysis of the 44 specific CHD surgical procedures showed that none of the hospitals were outliers for 30-day mortality (i.e. their outcomes were not outside the statistically acceptable limits of the STAT risk-adjustment model).

Key:

FRE	Freeman Road Hospital, Newcastle
GRL	Glenfield Hospital, Leicester
BRC	Bristol Royal Hospital for Children
SGH	Southampton General Hospital
OLS	Our Lady's Children's Hospital, Dublin
ACH	Alder Hey Children's Hospital, Liverpool
LGI	Leeds General Infirmary
GSTT	Evelina London Children's Hospital
BCH	Birmingham Children's Hospital
GOS	Great Ormond Street Hospital for Children

Average survival rates relative to prediction for adult CHD cases using the STAT model (2020/23)



Variability in post-procedural complication rates between hospitals may be accounted for in part by different case mixes

Although surgical mortality is a key indicator of performance, the rates of different complications after an operation are also important.

To reflect this, the audit captures data on si complications following CHD procedures:

- four are surgical-related (across 3,261 procedures)
- two involve interventional catheters (across 2,985 transcatheter interventions and 665 electrophysiology procedures).

Some very significant variations can be seen between centres, though making direct comparisons is challenging given their differences in case mix.

The audit has reviewed and refined the definitions of all complications and the first results from this will be published in 2024. Detailed case-mix and specific procedure-adjusted analysis can then be undertaken t establish best-practice for benchmarking between centres.

Percentage of procedures followed by one or more of six post-procedural complications (2020/23)

Hospital	ECMO	Renal support	Unplanned pacemaker	Prolonged pleural drainage	re
Birmingham Children's Hospital	3.40	1.80	1.20	3.10	
Bristol Royal Hospital For Children	1.70	7.60	1.80	2.80	
Dublin Our Lady's Children's Hospital	2.30	0.90	2.60	3.30	
Leeds General Infirmary	1.10	4.70	1.60	2.10	
Leicester Glenfield Hospital	3.80	0.20	0.60	0.60	
Liverpool Alder Hey Hospital	4.20	2.50	1.40	1.00	
London Evelina London Children's Hospital	0.90	4.00	0.80	1.00	
London Great Ormond Street Hospital for Children	2.30	2.70	0.90	1.90	
Newcastle Freeman Hospital	7.70	6.70	1.80	0.80	
Southampton Wessex Cardiothoracic Centre	1.20	1.20	1.20	1.20	
Total	2.50	3.10	1.30	1.80	

Over half of all procedures in infancy have a successful prenatal diagnosis

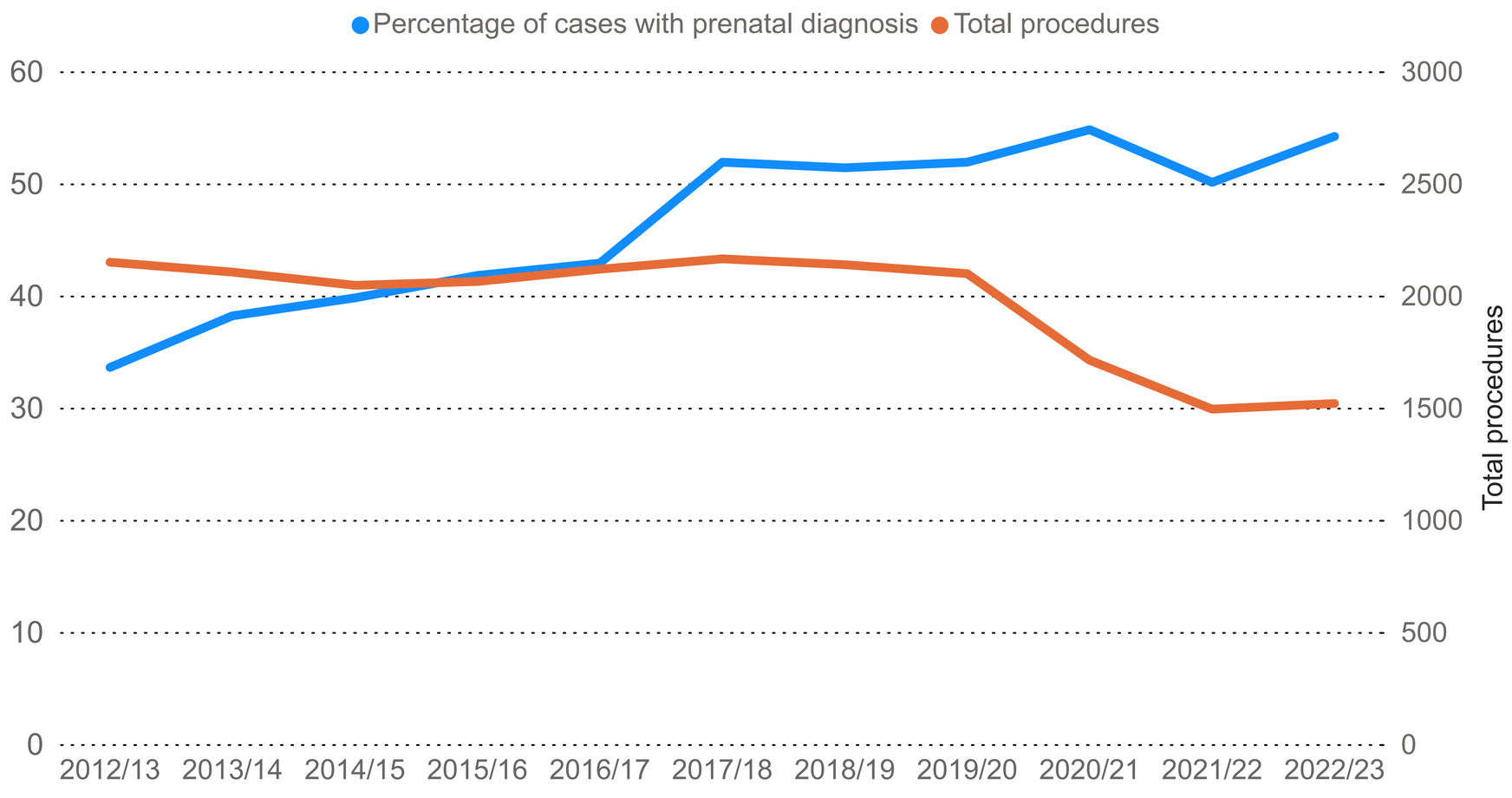
The audit collects data for babies diagnosed antenatally with a cardiac defect who then undergo an intervention in the first year of life.

In 2022./23, the detection rate was 54.2% for all infants requiring a procedure in the first year of life (up from 50.1% in 2021/22).

Over the last six years, the rate of antenatal diagnosis has plateaued at just over 50%.

Note: the data excludes spontaneous intrauterine deaths, termination of pregnancy, non-intervention after birth and unrecognised death in community or non-tertiary centre. For additional information, see here.

Percentage of CHD procedures in the first year of life for infants that had a prenatal diagnosis



Rates of prenatal diagnosis for CHD procedures vary nearly threefold across Integrated Care Boards and University Health Boards

The map demonstrates the variation in prenatal diagnostic rates for infants who underwent a procedure in the first year of life.

It covers:

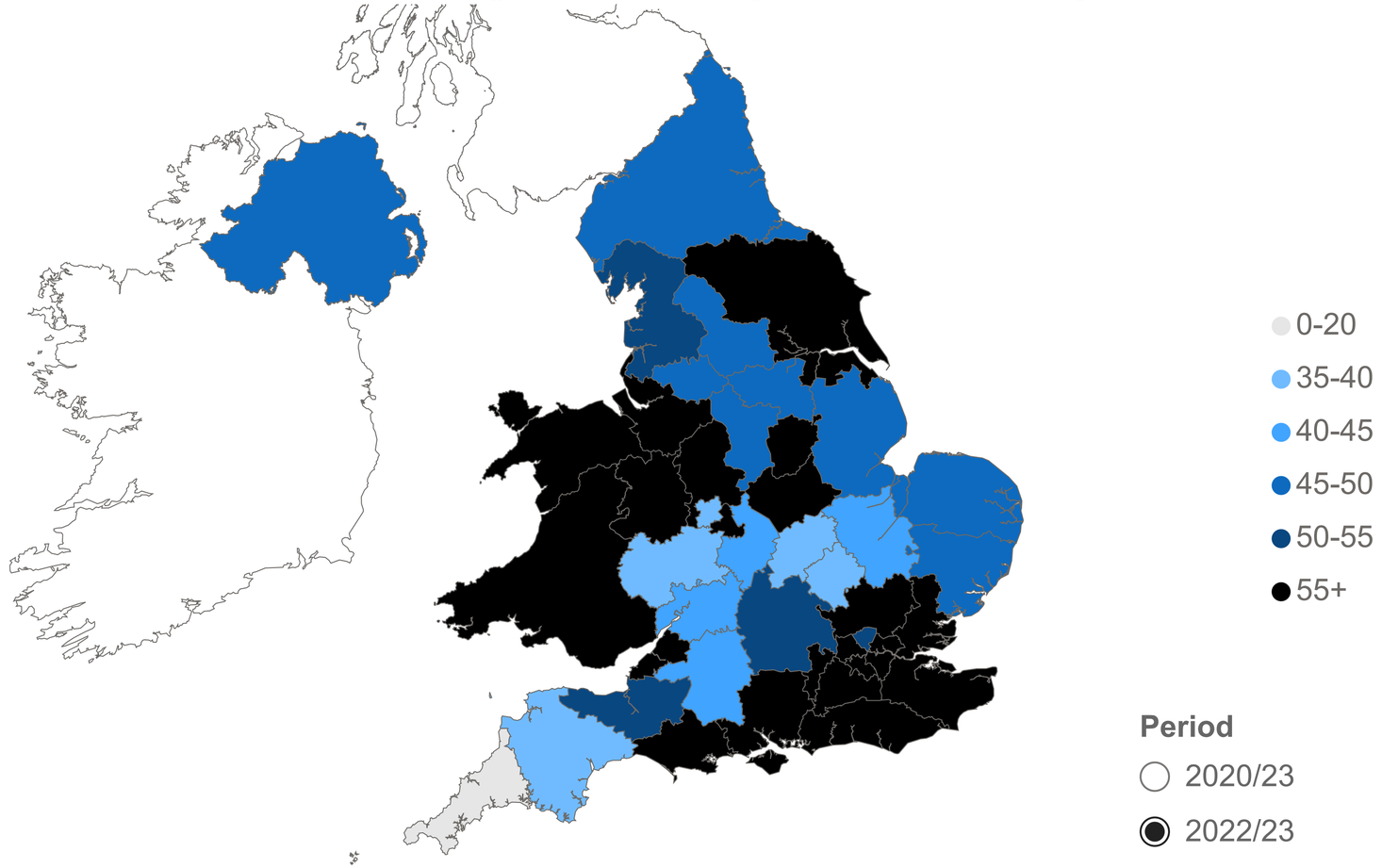
- 42 Integrated Care Boards (ICBs) in England
- seven University Health Boards in Wales
- Northern Ireland.

Data are provided for the financial year 2022/23 and for the three-year rolling period 2020/23.

Considerable variation can be seen in the three-year prenatal diagnosis rate, from 24% for the Cornwall and the Isles of Scilly Health and Social Care Partnership to 65% in South West London Health and Care Partnership.

For 2022/23, the highest rate of 72% was achieved by the Leicester, Leicestershire and Rutland ICB.

Percentage of CHD procedures in the first year of life for infants that had a prenatal diagnosis (one year and three year results)



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Prenatal diagnosis of lesions has improved for some types but worsened for others

The figure shows the prenatal detection rate of four individual cardiac lesions where a procedure is performed in the first year of life:

- Fallot's tetralogy
- Hypoplastic left heart syndrome (HLHS)
- Transposition of the great arteries with an intact intraventricular septum (TGA-IVS)
- Atrio-ventricular septal defect (AVSD)

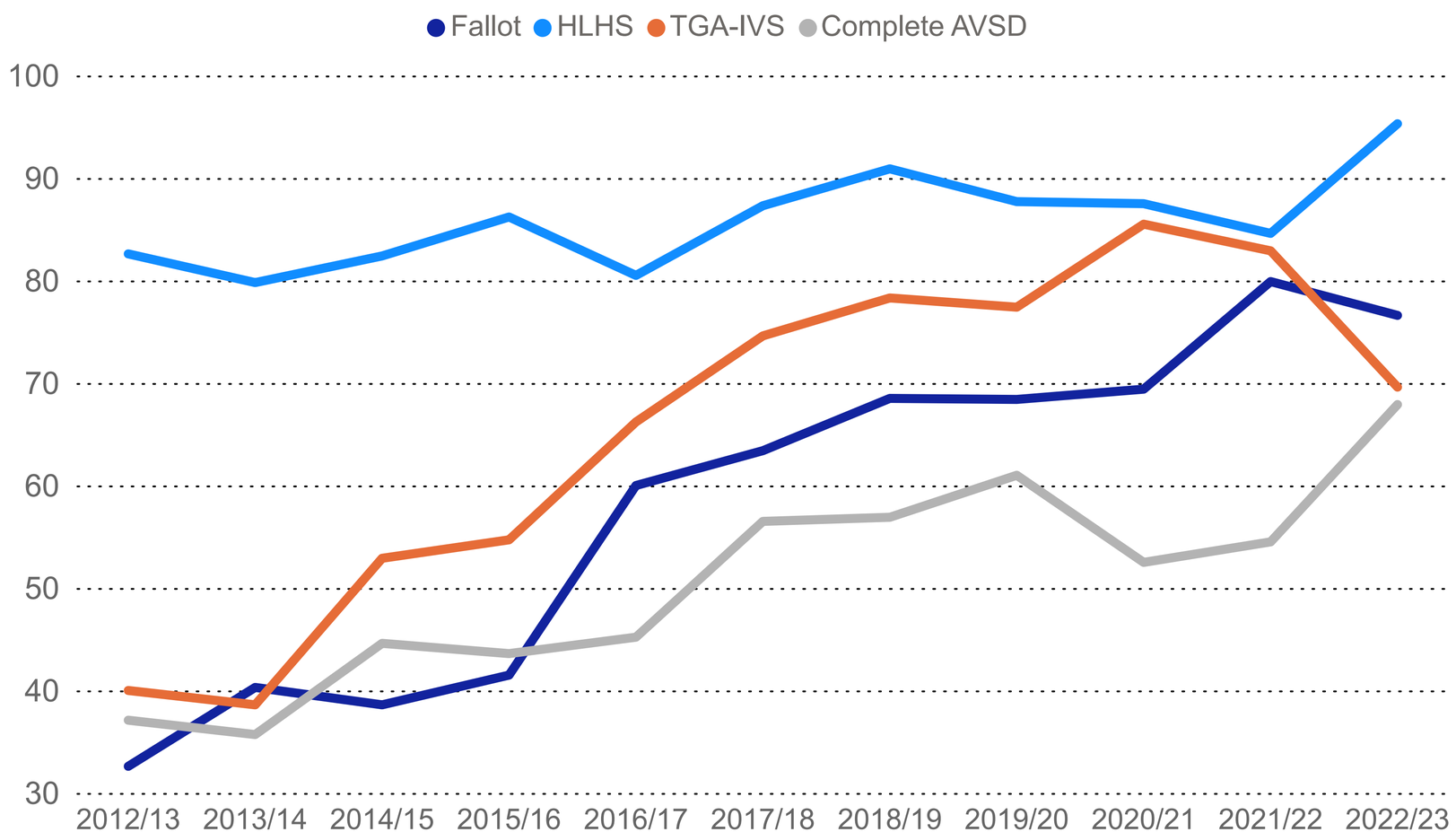
For those requiring a procedure in the first year, the prenatal detection of HLHS was highest in 2022/23 at 95%. There was also an improvement in diagnosis of complete AVSD.

Conversely, prenatal diagnostic rates for Fallot's tetralogy and TGA-IVS both deteriorated. This could represent a genuine fall in detection or might, for example, relate to an increase in the termination of pregnancy for these diagnoses. Linkage with the National Congenital Anomaly and Rare Disease Registration Service would help clarify such issues.

Differences in screening timing and methods used by sonographers may also drive variations in prenatal diagnosis.

A full table is available here (link to QI document).

Percentage of procedures in first year of life for infants with prenatal diagnosis by specific lesion



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

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This report is available via the NICOR website.