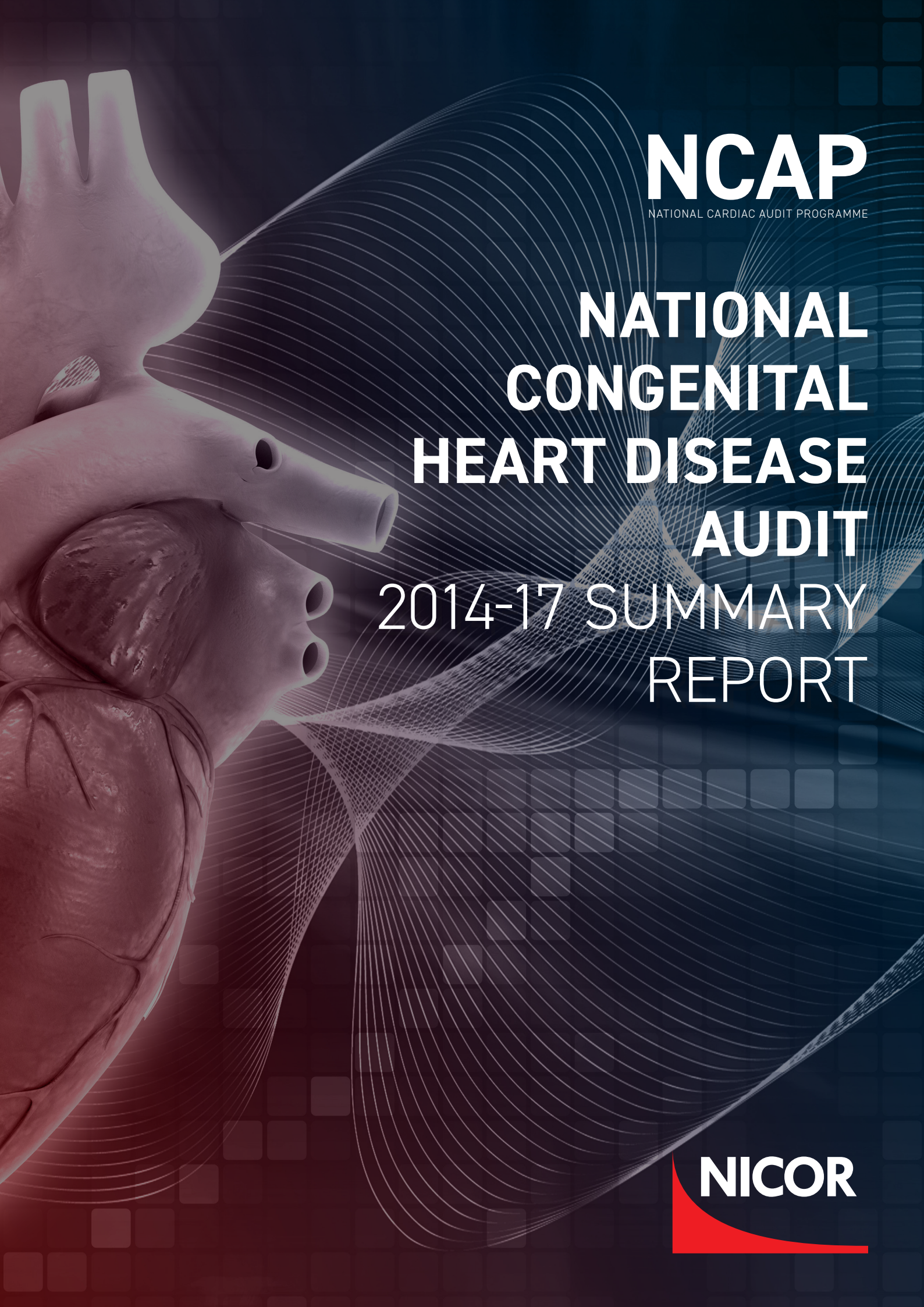

NCAP

NATIONAL CARDIAC AUDIT PROGRAMME

NATIONAL CONGENITAL HEART DISEASE AUDIT

2014-17 SUMMARY REPORT

NICOR

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BACKGROUND TO THE AUDIT

The National Congenital Heart Disease Audit (NCHDA) was set up in 2000. Originally referred to as the Central Cardiac Audit Database (congenital), it was developed to assess patient outcomes after therapeutic paediatric and congenital cardiovascular procedures (surgery, transcatheter and electrophysiological interventions) in the UK and the Republic of Ireland (since 2012). It is the largest comprehensive national audit of its kind in the world, with over 120,000 patients in the database (60% post-surgery). Data submission is mandatory and is collected from all centres undertaking such procedures in children and adults. In 2011 the Audit moved from being part of the NHS Information Centre, to being one of six audits brought together under the auspices of the National Institute for Cardiovascular Outcomes Research (NICOR), and, in 2017, as a Domain within the National Cardiac Audit Programme (NCAP).

THE PURPOSE OF THE AUDIT

The purpose of the national congenital heart disease audit (NCHDA) is to examine and improve service delivery for, and outcomes of, infants, children, adolescents and adults undergoing interventions for paediatric and congenital heart disease.

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

The dataset for each NCAP audit broadly follows the 'clinical pathway' from admission of patients to hospital until their discharge.

The required data items are routinely reviewed to reflect the changing needs of the congenital heart services community and are designed to answer the following key questions:

- how is treatment delivered across the country, including the number of hospitals delivering services and the volume of procedures undertaken?
- which specific procedures are provided to treat children with heart disease and congenital heart disease at any age: surgery, transcatheter interventions and electrophysiological procedures?
- what clinical outcomes are associated with these treatments and are there steps to be taken to improve on these?

ABOUT THE NCHDA

The NCHDA collects data from all centres undertaking paediatric and congenital cardiac surgery and interventional procedures, including electrophysiology, in the United Kingdom and Republic of Ireland (RoI). The Audit focuses on monitoring activity levels and outcomes following congenital cardiovascular procedures at any age, and for patients under 16 years of age with acquired heart disease who undergo interventions, as well as the success of antenatal diagnostic screening. The NCHDA dataset is designed by clinicians working in collaboration with two professional societies: the British Congenital Cardiac Association (BCCA) and the Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS). Members of the professional societies support the NCHDA Clinical Lead, together with representation from patients, allied health professionals, and commissioners all working together with the NCAP delivery team on the NCHDA Domain Expert Group to help establish the direction of the audit programme.

1 QUALITY ASSURANCE AND QUALITY IMPROVEMENT

This report heralds an even stronger focus on identifying and communicating the quality improvement learning from the NCAP audit. The resulting data provide a means of driving up the quality of care in all hospitals, and for all operators, to the standards or benchmarks that are already known to be achievable (quality improvement), ensuring that high quality services are maintained (quality assurance) and raising the standards of care over time by identifying changes in the way care is provided and measuring whether these changes are associated with better outcomes for patients.

As with the wider report, this summary is also focused on the same quality improvement themes:

- Patient outcomes – how good are the outcomes for patients and how can we improve these?
- Safety – how can services be made safer?
- Clinical effectiveness – are the best clinical protocols and treatments being used?

These highlight the value and continued opportunities for quality improvement from comprehensive, longitudinal national audit. The specific metrics captured by the NCHDA that relate to these quality themes are shown in Table 1 below.

As with the aggregate NCAP report, this summary also focuses on these quality improvement themes and does not describe all the data available. The complete analyses, and audit methodology are available here.

2 ANALYTICAL SCOPE OF THE NATIONAL CONGENITAL HEART DISEASE AUDIT

Congenital heart disease services are a relatively small specialty accounting for just over 1% of the NHS specialised commissioning budget. Due to the relatively small number of cases involved with a large number of different procedures, the audit provides composite 3-year outcome analyses, to both allow meaningful comparison of units and minimise the risk of identifying individuals. This is in line with the Office for National Statistics (ONS) Confidentiality Guidance for publishing health statistics.

The CHD results cover 3 different time periods:

- 2016/17: including data collected from April 1st 2016 - 31st March 2017, which has not been reported on in any previous report.
- 2014/15-2016/17: is the standard reporting period for metrics related to the Congenital audit.
- 2007/8-2016/17: is used to demonstrate longer term trends as necessary.

Overview of themes and metrics

A brief description of the separate specialties that provide data for the NCAP is provided in Appendix A of the main report (**link**). Appendix B of that report summarises the methodology used (**link**). The selected metrics for the Congenital audit report are shown in Table 1.

Table 1: Selected metrics for the Congenital Audit

Type of metric	Congenital Audit [NCHDA]
Outcomes	30-day risk-adjusted mortality: • Aggregate 30-day mortality for all paediatric cardiac surgery procedures, risk adjusted using PRAiS2 methodology • 30-day mortality for 83 individual procedures, surgical, electrophysiological and interventional, in children and adults
Safety	Number of procedures (Paediatric/adult): • Overall • Surgical • Interventional • Electrophysiology (EP)
Effectiveness	Antenatal detection and diagnosis: • Overall in those requiring an intervention in infancy • For two specific diagnoses: hypoplastic left heart syndrome (HLHS); and transposition of the great arteries with intact ventricular septum (TGA-IVS)

3 KEY QUALITY IMPROVEMENTS FROM THE NATIONAL CONGENITAL HEART DISEASE AUDIT

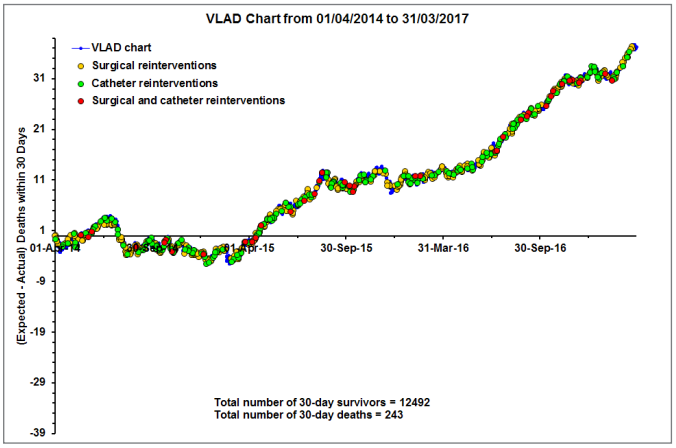
3.1 IMPROVEMENTS TO OUTCOMES

Hospitals providing care for children with congenital heart disease have low levels of 30-day mortality. Survival rates are high, and the analysis shows that the observed outcomes continue to be better than those predicted. It is not fully clear whether this represents a true improvement in outcome or differences in outcomes brought about by an inability of the risk model to account for variations in case mix, or improved data collection of associated risk factors such as non-cardiac diseases, but the trend is encouraging.

3.1.1 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, so as to identify potential areas of concern or strengths, thereby enabling improvements in patient safety and quality of care to be initiated. 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 2009-2015 Congenital Audit outcomes, with improved statistical performance.[1]

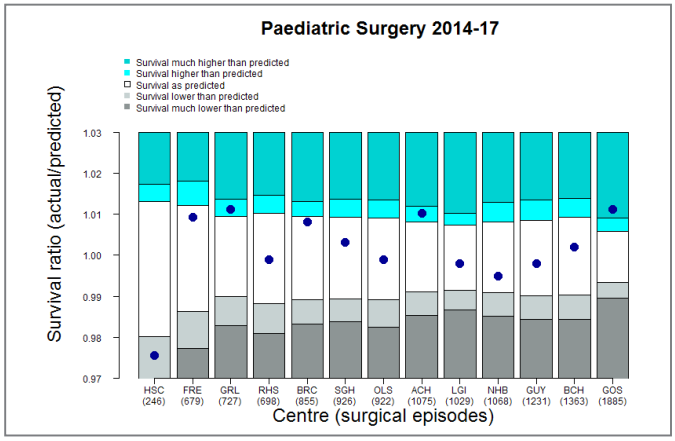
Figure 1: Variable Life Adjusted Display (VLAD) Chart for all 13 paediatric centres in UK and Republic of Ireland undertaking procedures in patients under 16 years of age, 2014/15-2016/17



The risk model (PRAiS2) essentially benchmarks the unit's outcomes against recent national outcomes in paediatric heart surgery accounting for all the important medical aspects of case mix complexity. A positive value (line going up) indicates improved survival in comparison with what would be predicted based on case mix. So, the estimated risk of death for a patient is small and this means that the VLAD will rise much more slowly for a run of survivors than it will fall for a run of deaths. Despite this being one of the most complex areas of surgery and lifesaving for the children involved, the UK and Republic of Ireland have excellent outcomes with very low mortality rates.

This VLAD chart depicted in the report represents national outcomes between 2014 and 2017, with surgical procedures represented by the blue 'VLAD chart' line. This chart follows a reasonably horizontal track from early 2014 until 2015, indicating that outcomes during this period are on a par with what would be expected based on the PRAiS2 risk model. This is not surprising since the PRAiS2 risk model was developed using data from this era. The VLAD chart line from 2015-2017 rises above the baseline, indicating the observed 30-day outcomes during this period were better than predicted. Looking at this more closely we can determine that between 2015 and 2017 based on the PRAiS2 risk model it would be predicted to see 186 deaths whereas there were actually only 147 deaths. Although the VLAD trend is encouraging, it is important to note that the model and assessment of life status is based on mortality within 30 days of a surgical procedure and therefore does not take into account deaths which may have occurred in hospital after 30 days.

Figure 2: Actual vs Predicted Survival Rates for all 13 centres in the UK and Republic of Ireland undertaking procedures in patients under 16 years of age 2014-2017 using PRAiS2 risk adjustment methodology.



Abbreviations: HSC, London, Harley Street Clinic; FRE, Newcastle, Freeman Hospital; GRL, Leicester, Glenfield Hospital; RHS, Glasgow, Royal Hospital for Sick Children; BRC, Bristol, Bristol Royal Hospital For Children; SGH, Southampton, Wessex Cardiothoracic Centre; OLS, Dublin, Our Lady's Children's Hospital; ACH, Liverpool, Alder Hey Hospital; LGI, Leeds, Leeds General Infirmary; NHB, London, Royal Brompton Hospital; GUY, London, Evelina London Children's Hospital; BCH, Birmingham, Birmingham Children's Hospital; GOS, London, Great Ormond Street Hospital for Children.

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

The VLAD chart also displays all surgical or catheter based re-interventions that occur within a 30-day episode of surgical management (see colour key on the chart in Figure 1 for types of re-intervention). These displays enable clinical teams to identify and review clusters of re-interventions following a review of VLAD charts within regular governance or morbidity conferences (usually monthly). Some of these will be planned re-interventions, but the focus by the centres will be on any unplanned additional procedures that are highlighted by the VLAD chart, and any quality improvement measures that can be

taken forward to avoid these in future. A full interpretation of the VLAD chart can be found here (link).

Figure 2 on page 4 shows the 30-day risk adjusted survival rates at centre level using whole program aggregated data, with risk adjustment using PRAiS2 methodology and software. Paediatric cardiac surgical procedures are defined as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years, excluding lung transplant, extracorporeal and mechanical life support procedures and minor/non-cardiovascular procedures. The y-axis of the figure shows the survival ratio (actual survival/predicted survival) for all units, and the x-axis the number of surgical 30-day episodes. The dot represents the actual performance of a unit. The shaded bars represent the alarm and alert limits (99.5% and 97.5% respectively) control limits. The performance of units falling in or above the white area, indicates survival is the same, or above, that predicted by the PRAiS2 risk adjustment model. It is important to note that as there are only 13 centres in the paediatric analysis this means that there is a 25.5% risk of at least one centre being beyond the alert limit and a 1.35% chance of being beyond the alarm limit by random chance (i.e. a false positive or negative outlier). See also Table 2. For a more detailed, plain language explanation, see the "Understanding Children's Heart Surgery" website.

Table 2: Actual and Predicted Survival Rates 2014-17, using PRAiS Risk Adjustment methodology, for all 13 units undertaking procedures in patients under 16 years of age.

Hospital name	Hospital code	Surgical episodes	Actual survival	Predicted survival	Actual/predicted survival	Survival summary
London, Harley Street Clinic	HSC	246	236	98.3%	0.976	lower than predicted
Newcastle, Freeman Hospital	FRE	679	666	97.2%	1.009	as predicted
Leicester, Glenfield Hospital	GRL	727	721	98.1%	1.011	higher than predicted
Glasgow, Royal Hospital for Sick Children	RHS	698	683	98.0%	0.998	as predicted
Bristol Royal Hospital for Children	BRC	855	844	97.9%	1.008	as predicted
Southampton, Wessex Cardiothoracic Centre	SGH	926	908	97.8%	1.002	as predicted
Dublin, Our Lady's Children's Hospital	OLS	922	900	97.7%	0.999	as predicted
Liverpool, Alder Hey Children's Hospital	ACH	1075	1063	97.9%	1.01	higher than predicted
Leeds General Infirmary	LGI	1029	1012	98.5%	0.998	as predicted
London, Royal Brompton & Harefield Hospital	NHB	1068	1040	97.9%	0.994	as predicted
Evelina London Children's Hospital	GUY	1231	1195	97.3%	0.997	as predicted
Birmingham Children's Hospital	BCH	1363	1324	96.9%	1.002	as predicted
London, Great Ormond Street Hospital for Children	GOS	1885	1869	98.1%	1.011	much higher than predicted

The results in table 2 show that over the last 3 years, all but one hospital – the Harley Street Clinic - has performed to the level predicted or better than predicted (30-day survival as predicted or better than the control limits for aggregated outcomes after all surgical procedures); the Harley Street Clinic is within the negative Alert level band.

Two centres performed 'better' and one centre (Great Ormond Street Hospital in London) 'much better' than predicted for the third year running. This is indicative of good performance and represents an opportunity for sharing more optimal practice across specialist centres. Whilst this continues to be very reassuring news for patients and families, as well as other stakeholders such as commissioners, it must underpin a commitment to move beyond 30-day survival rates and to explore methods to assess longer term survival, the incidence of post-procedural complications, and other measures of outcome such as quality of life in survivors (see section 5 of the main report). From April 2015 the Congenital Audit dataset was updated to support these goals with several additional fields: post-operative and post-interventional procedure complications and documenting if additional procedures are expected or unexpected with respect to the individual patient's care management pathway. Data on these new fields is planned to be reported after the first three-year cycle has been completed in the NCHDA 2015-18 report.

3.1.2 30-DAY SURVIVAL AFTER 83 SPECIFIC PROCEDURES

Survival at 30 days was analysed for 83 major surgical, transcatheter cardiovascular and electrophysiological interventions undertaken to treat congenital heart disease at any age (children and adults analysed separately), excluding minor and non-cardiovascular procedures. This is a considerable

increase from the previous 57 procedures reported in 2011-14 and the 72 procedures reported in 2013-16. In all hospitals 30-day survival was better than the alarm limit (99.5%) for all procedures and, in all but three hospitals, was better than the alert limit (97.5%). Two centres demonstrated a hangover effect from the previous 2013-16 analysis due to the Audit reporting rolling three-year outcomes, with no additional mortality for these procedures in 2016-17. Although the overall results for Great Ormond Street Hospital are excellent (see above), this hospital had results beyond the 98% confidence 'alert' limit for transcatheter procedures involving systemic to pulmonary collateral arteries. NICOR wrote to Great Ormond Street suggesting a review for this transcatheter procedure be undertaken, to consider the cases involved and, if relevant, document resultant changes in practice. This was received and documents that the two deaths in this category had highly complex cardiopulmonary anatomy and the deaths were not related directly to this procedure. Their summary report is linked to this procedure as published on the NCHDA web portal. To see the volume of activity for procedures and specific procedures for individualised congenital heart centres, click here.

3.1.3 OUTLIER POLICY

NICOR follows the Department of Health Outlier Policy,[2] which sets out a process for providing assurance that all hospitals provide the expected quality of care. This policy is initiated when the results are outside the predicted range for risk adjusted PRAiS2 outcomes and if they breach the Alert or Alarm confidence limits for the outcome after a specific procedure. Centres that fall outside the expected range are sometimes referred to as 'outliers'. NICOR is required to notify NHS England of any outlier hospitals within England and Wales. The hospital whose aggregate results are lower than expected has been contacted by NICOR and the relevant professional societies informed, recommending a review and summary of the cases involved. The response from the hospital will be reviewed by members of the Congenital Audit Domain Expert Group including the President of the British Congenital Cardiac Association (BCCA) and congenital cardiology lead for the Society for Cardiothoracic Surgery (SCTS).

3.2 IMPROVEMENT TO SAFETY

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 and commissioners have recommended certain minimum volumes of activity at hospitals for particular services, including congenital heart disease.

An expert group of commissioners, clinicians and regulators have suggested minimum volumes of activity for individual operators and, by implication, hospitals undertaking congenital heart procedures.[3]

ALL PROCEDURES

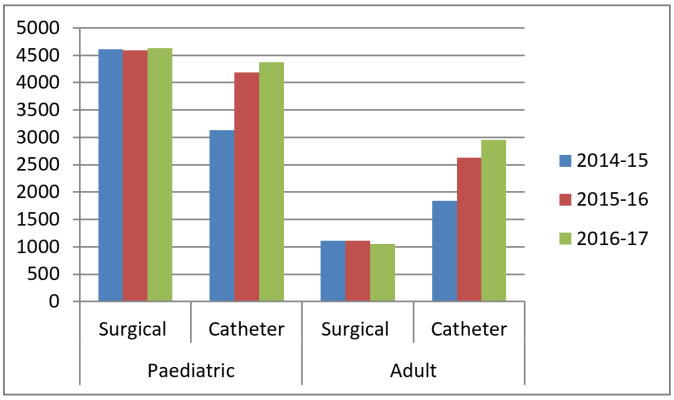
In 2016-17, UK and RoI centres submitted data on 13,018 procedures where 9,011 were paediatric cases and 4,007 were adult congenital heart cases. There is a continuing rise in catheter-based procedures. A full breakdown of 30-day outcomes by age group for all procedures (2014/5-2016/17) is available on the NCHDA website.

Table 3: Total number of cases submitted to the NCHDA in financial years 2003-17

Year	Surgical	Hybrid	Catheter			Diagnostic Catheter	Total
			Interventional	EP/Pacing	ICD		
2003-04	4497	0	2928	-	-	-	7425
2004-05	4346	0	3032	-	-	-	7378
2005-06	4638	3	3490	-	-	-	8131
2006-07	4794	7	3769	-	-	-	8570
2007-08	4771	10	3616	-	-	-	8397
2008-09	4949	14	3910	-	-	-	8873
2009-10	5262	6	3963	-	-	-	9231
2010-11	5852	6	4310	-	-	-	10168
2011-12	5710	29	4498	-	-	-	10237
2012-13	5849	16	4372	-	-	-	10237
2013-14	6024	50	3720	944	109	-	10847
2014-15	5662	62	3511	1037	117	-	10389
2015-16	5630	53	3731	1347	126	1631	12518
2016-17	5642	48	3837	1459	154	1878	13018

Note: *Primary Extracorporeal Membranous Oxygenation (ECMO), Ventricular Assist Devices (VAD) and lung transplants are counted as surgical activity; interventional, Electrophysiology(EP)/Pacing and Implantable cardioverter-defibrillator (ICD) devices are counted as catheter procedures, collated separately until 2013/14 financial year. 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 data set from 2015-16 onwards.*

Figure 3: Surgical and catheter-based procedures submitted to the NCHDA in financial years 2014-17



The activity over the last three years shows a plateau of surgical activity but increasing transcatheter and electrophysiological activity, as an aggregate, in the UK and Republic of Ireland.

The organisation of congenital cardiac services is based on national standards.[4] There are currently no data to show the effect of implementing these recommendations across the country, but the expectation is that the higher volumes will deliver a more consistent and sustainable service with the appropriate infrastructure to treat these complex patients. Previous analysis of the Congenital audit data was not able to identify a statistically-significant volume-outcomes relationship for UK centres undertaking paediatric cardiac procedures, although there was a definite trend to support better outcomes in larger centres. This supports the way that congenital heart centres have been commissioned in the UK over the last decade, not allowing NHS centre volumes to fall to the low numbers that can occur in other countries (including the USA). The NHS England national standards for manpower, related procedural volume and infrastructure are based on the expectation that this will ensure a consistent and sustainable service to help continue to improve the outcomes for these complex patients.

The NHS England review concluded that not all English centres treating children and adults fully met the current requirements. Hospitals undertaking congenital cardiac surgery should continue to work with specialist commissioners and aim to meet the NHS England Standards, which will be reviewed again in three years' time.

Volume of activity is not the only consideration for good outcomes and there are other issues to consider. These include the sustainability of services, the numbers of support staff, the infrastructure needed and the frequency of on-call commitments. However, the reported performance of hospitals or clinicians is less likely to be influenced by a small number of atypical cases when the overall number of cases is large.

3.3 IMPROVEMENTS TO CLINICAL EFFECTIVENESS

3.3.1 ANTENATAL DIAGNOSIS

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.[5]

A goal of congenital heart disease services is to diagnose heart disease as early as possible and the ideal is before birth, referred to as antenatal diagnosis. Poor antenatal diagnosis rates are associated with limited opportunity to counsel expectant patients and worse outcomes for babies.[6] We do not yet know what proportion of children with CHD are diagnosed antenatally (NICOR is working with Public Health England to develop better measures) but we do know this for those children who have a procedure in the first year of life. Amongst this group, detection continues to improve – more than 4 in 10 of these children are now antenatally diagnosed.

Antenatal diagnoses require sophisticated ultrasonography equipment and highly skilled obstetric sonographers to acquire and interpret the images. A robust and swift referral system to fetal cardiologists is also required to make a definitive diagnosis, decide upon a management pathway for the pregnancy, provide counselling and support for the parents and coordinate postnatal care.[7]

Table 4: Proportion of patients undergoing procedures in infancy successfully diagnosed antenatally (2007/8-2016/17).

Financial years 2007-2016		
Year	**Total number of patients undergoing procedure(s) in infancy**	**% Antenatally diagnosed**
2007	1896	29.6%
2008	1789	29.3%
2009	2003	29.8%
2010	2260	31.3%
2011	2196	34.9%
2012	2240	34.8%
2013	2195	39.0%
2014	2127	40.4%
2015	2157	42.6%
2016	2231	43.5%
Total	21094	35.7%

The latest audit data for 2016/17 shows a continued improvement in antenatal detection rates of infants requiring a procedure with a successful antenatal detection (Table 4 and Figure 4). These figures cannot be directly compared to earlier reports from NICOR as previously the analyses looked at the number of procedures in infancy where an antenatal diagnosis had been made (over 50% in 2015-16). The Audit is now using the more appropriate metric of how many infants had had an antenatal diagnosis irrespective of how many procedures they may have had in the first year of life (excluding isolated procedures for a secundum atrial septal defect or persistent patent arterial duct, as these cannot be diagnosed before birth). This means that the same patient who may have had more than one procedure in infancy, is no longer counted more than once. It is important to also understand that these figures are probably an underestimate of the national antenatal detection rates as they do not take into account four scenarios: 1. fetal deaths that may occur during pregnancy (spontaneous or termination of

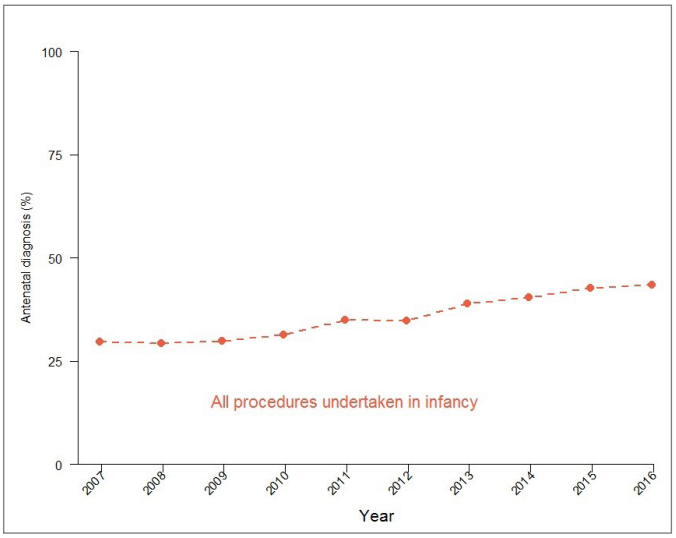
pregnancy); 2. perinatal deaths before a procedure was possible; 3. less severe malformations that did not require a procedure in infancy; and 4. where a decision is made not to intervene due to the complexity of the heart abnormality or associated comorbidities (compassionate care).

Antenatal detection rates are much higher for babies with more severe, functionally single ventricle lesions (such as hypoplastic left heart syndrome), as such defects are more easily seen by the obstetric sonographer.[8] However, many important congenital heart malformations, especially where the great arteries are not normal, are technically more difficult to detect. Mandatory antenatal detailed screening for abnormalities of the great arteries has only relatively recently been introduced by the NHS Fetal Anomaly Screening Programme.[9]

The Congenital Audit has looked at the overall detection rates of congenital heart disease in all infants requiring an intervention, and this year also examined the success of antenatal screening to detect two contrasting specific heart malformations:

- hypoplastic left heart syndrome (HLHS) - with a functionally single ventricle circulation
- transposition of the great arteries with an intact ventricular septum (TGA-IVS).

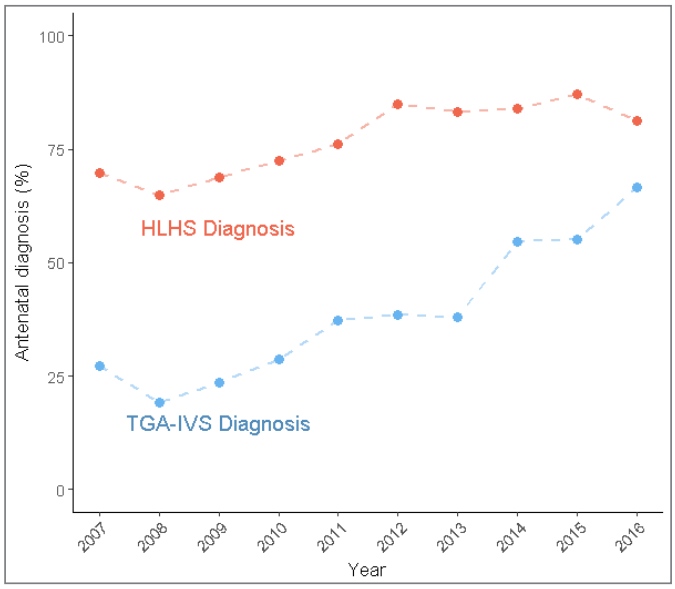
Figure 4: Proportion of patients undergoing procedures in infancy successfully diagnosed antenatally (financial years 2007/8-2016/17)



Footnote to Figure 4 and 5: Note that the methodology has changed this year. Calculations are based on the number of individual patients with an antenatal diagnosis and a first procedure in infancy (previously based on any procedure in infancy), excluding isolated procedures for a secundum atrial septal defect or persistent patent arterial duct.

In both conditions, infants often need an emergency procedure within hours of delivery followed by major surgery within a few days of birth. Research has shown that an antenatal diagnosis improves survival with fewer complications and better neurocognitive outcomes.[10,11] An antenatal diagnosis will impact on the place and timing of delivery with care often transferred to the tertiary congenital heart centre or the nearest obstetric unit, so that the paediatric cardiologist can be rapidly at the bedside if required.

Figure 5 – Proportion of patients with two specific congenital heart malformations requiring a procedure within 6 months of birth with a successful antenatal diagnosis (financial years 2007/8-2016/17). ***Note:*** *HLHS = hypoplastic left heart syndrome; TGA-IVS = transposition of the great arteries with an intact ventricular septum.*



This shows an expected high diagnosis rate for hypoplastic left heart syndrome, rising from about 65% 10 years ago to over 80% in recent years. There has also been a significant increase in the rate of diagnostic success for transposition of the great arteries with an intact ventricular septum, rising from just 26% in 2007-08 to nearly 65% in 2016-17, consistent with international figures.[12] Note again that these figures are likely an underestimate given the four scenarios outlined above wherein the Audit does not have antenatal detection rate data (of most relevance to those with a diagnosis of hypoplastic left heart syndrome).

This is likely to have had an important influence on the outcomes after the arterial switch procedure, not only with respect to mortality, but also to pre- and post-procedural morbidity and support for families, as described in the patient story in the main NCAP report. However, there remains considerable regional variation, especially for transposition of the great arteries with only 20% detection rate in some regions compared with 80% or more in others. The considerable rise in detection rates in the last 3 years for transposition of the great arteries illustrated in Table 5 below, corresponds to the introduction of the mandatory 3-vessel and tracheal view in 2016 to the fetal cardiac sonographer protocol and the preceding 2-year national training programme.[9]

Table 5: Regional variation in antenatal diagnosis of two specific conditions 2014-15 to 2016-17.

Local Area Team	TGA -IVS diagnosis	% Antenatally diagnosed	HLHS diagnosis	% Antenatally diagnosed
Channel Islands	1	0.0%	-	-
Q44. Cheshire, Warrington and Wirral	2	50.0%	5	80.0%
Q45. Durham, Darlington and Tees	3	33.3%	5	100.0%
Q46. Greater Manchester	4	100.0%	12	83.3%
Q47. Lancashire	1	100.0%	4	100.0%
Q48. Merseyside	2	100.0%	1	100.0%
Q49. Cumbria, Northumberland, Tyne and Wear	4	50.0%	9	100.0%
Q50. North Yorkshire and Humber	9	66.7%	6	100.0%
Q51. South Yorkshire and Bassetlaw	14	57.1%	3	33.3%
Q52. West Yorkshire	17	41.2%	9	77.8%
Q53. Arden, Herefordshire and Worcestershire	5	20.0%	12	83.3%
Q54. Birmingham and The Black Country	6	33.3%	22	100.0%
Q55. Derbyshire and Nottinghamshire	8	50.0%	8	87.5%
Q56. East Anglia	7	42.9%	4	100.0%
Q57. Essex	8	75.0%	3	100.0%
Q58. Hertfordshire and The South Midlands	13	69.2%	12	91.7%
Q59. Leicestershire and Lincolnshire	10	30.0%	8	75.0%
Q60. Shropshire and Staffordshire	5	20.0%	6	83.3%
Q64. Bath, Gloucestershire, Swindon and Wiltshire	0	-	5	100.0%
Q65. Bristol, North Somerset, Somerset and South Gloucestershire	0	-	6	100.0%
Q66. Devon, Cornwall and Isles of Scilly	0	-	2	100.0%
Q67. Kent and Medway	5	100.0%	7	100.0%
Q68. Surrey and Sussex	10	80.0%	7	85.7%
Q69. Thames Valley	6	50.0%	10	90.0%
Q70. Wessex	4	50.0%	5	100.0%
Q71. London	35	80.0%	35	82.9%
Republic of Ireland	35	54.3%	48	77.1%
Northern Ireland	0	-	11	90.9%
Scotland	12	58.3%	12	75.0%
South Wales	1	100.0%	3	100.0%
North Wales	0	-	2	100.0%
Unknown	6	33.3%	15	33.3%
Total	233	58.4%	297	84.2%

HLHS = hypoplastic left heart syndrome; TGA-IVS = transposition of the great arteries with an intact ventricular septum

Table 6: 10 year detection rates for HLHS and TGA-IVS

2007-2016		
Year	**HLHS diagnosis**	**% Antenatally diagnosed**
2007	112	69.6%
2008	91	64.8%
2009	109	68.8%
2010	94	72.3%
2011	113	76.1%
2012	99	84.8%
2013	107	83.2%
2014	106	84.0%
2015	100	87.0%
2016	91	81.3%
Total	1022	77.2%

2007-2016		
Year	**TGA-IVS diagnosis**	**% Antenatally diagnosed**
2007	92	27.2%
2008	83	19.3%
2009	89	23.6%
2010	101	28.7%
2011	83	37.3%
2012	86	38.4%
2013	84	38.1%
2014	77	54.5%
2015	87	55.2%
2016	69	66.7%
Total	851	38.0%

HLHS = hypoplastic left heart syndrome; TGA-IVS = transposition of the great arteries with an intact ventricular septum

It is important to ensure that feedback mechanisms and links are in place between the Congenital Audit, the fetal cardiology community and antenatal ultrasound scanning departments to enable learning related to congenital heart cases which have not been detected. The audit will facilitate this by passing on these results to the UK National Fetal Cardiology Group and Tiny Tickers Charity, enabling its members to target individual centres most in need of improvement for staff training and optimisation of ultrasonography equipment. Results will also be shared with the relevant Clinical Commissioning Groups (CCGs).

4 DRIVING FUTURE QUALITY IMPROVEMENT THROUGH AUDIT

Next year, it is anticipated that the design and conduct of the NCAP Audits will continue to evolve to inform and drive future quality improvement.

The Congenital Audit reviews the care for a smaller number of patients than the other cardiac audits and this provides its own challenges in statistical analysis. This is one of the reasons why data are analysed over a three-year rolling programme, allowing the collection of data on sufficiently large groups of patients undergoing a variety of specific procedures to allow for reliable comparisons. Given the large number of different cardiac malformations with associated specific surgical and/or transcatheter procedures, relatively small variations in data quality can result in different conclusions about the quality of care. This Audit has developed a unique data quality index which provides confidence in the data submitted and their analyses. It has also developed a unique risk model (PRAiS2) that allows hospitals to see how they are doing with respect to their own patient case mix, comparing monthly outcomes to what is predicted nationally and in their own practice.

4.1 DATA VALIDATION AND DATA QUALITY INDICATOR SCORES FOR 2016-17 DATA

All paediatric centres and larger adult centres have site visits by an external volunteer congenital cardiology consultant (cardiologist or cardiac surgeon) or a senior congenital cardiology trainee. The NHCDA Clinical Auditor links live to the site visit by Skype. There are three stages to the site validation process. The first involves a review of 20 randomly selected hospital records of congenital patients. Previously submitted NCHDA data for the same 20 patients are cross-checked against their hospital notes. After the checking process the hospital receives a quality score (the Data Quality Indicator (DQI)) on the case note validation. The DQI is a measure of the accuracy and completeness of data entry across four domains (i.e. demographics, pre-procedure, procedure and outcome), which ideally is expected to be greater than 90%. The second stage assesses the theatre and catheter laboratory logbooks. These are examined to ensure all appropriate cases have been submitted (case ascertainment), with correct procedure and diagnosis coding, adding and deleting cases as appropriate. The third stage examines the records of all deceased cases in the audit year to ensure the accuracy of diagnoses, procedure(s) undertaken and any additional comorbid factors, again comparing against the data submitted.

Remote validation is used for relatively small volume centres only undertaking adult congenital heart procedures. It involves a series of checks with the centre that include reviewing the data before the first round of analysis and confirmation of the number of specific procedures and deaths. Case notes are not examined and therefore no DQI is generated for these centres.

The NCHDA minimum standard for data quality is 90% accuracy. Nearly all centres had DQI scores of 90% and above (Table 6a and 6b). Above 95% is excellent (shown in bold). Overall the average DQI has improved year on year for paediatric centres, although it is more erratic for adult (ACHD) centres. Importantly the 2017 site visits looking at 2016-17 data have shown that for the first time all centres receiving an on-site validation visit had an overall DQI score of over 90%. The previous exception was Queen Elizabeth Hospital, Birmingham with an overall DQI score of 75% in 2015-16, but this year their DQI has risen to 92.5%, following improved staffing, with protected time to monitor quality and accuracy of all ACHD data. The centre site visit reports are available on the NCHDA website.

DATA QUALITY INDICATOR (DQI) TABLES 2014-17

Table 6a Paediatric and Mixed Practice Hospitals

DQI% for 14/15 data based on the 20 case note review May 15 - Feb 16				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Belfast Royal Victoria	RVB	98.75	99.75	98.25
Birmingham Children's Hospital	BCH	98.5	98.5	98
Bristol Royal Hospital for Children	BRC	94.50	95	94
Dublin, Our Lady's Children's Hospital	OLS	97.25	97.75	96
Glasgow Royal Hospital for Sick Children	RHS	98.5	99.5	96.5
Leeds General Infirmary	LGI	97	97.25	96
Leicester, Glenfield Hospital	GRL	94	92.7	97
Liverpool, Alder Hey Children's Hospital	ACH	97.25	96.5	98
London, Evelina London Children's Hospital for Sick Children	GUY	97.5	98.5	98
London, Great Ormond Street Hospital for Children	GOS	99.5	99.5	99.5
London, Harley Street Clinic	HSC	94.5	96.5	86
London, Royal Brompton & Harefield Hospital	NHB	99	98.75	97.75
Newcastle, Freeman Hospital	FRE	97.25	97.25	97
Southampton, Wessex Cardiothoracic Centre	SGH	97.5	98	97.5

DQI% for 15/16 data based on the 20 case note review May-Nov 2016				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Belfast Royal Victoria	RVB	98.25	98.25	98.5
Birmingham Children's Hospital	BCH	97.75	98.75	96.75
Bristol Royal Hospital for Children	BRC	98.60	99.25	98.25
Dublin, Our Lady's Children's Hospital	OLS	94.5	94.25	95
Glasgow Royal Hospital for Sick Children	RHS	99.25	98.75	99.25
Leeds General Infirmary	LGI	97. 75	98.5	97.25
Leicester, Glenfield Hospital	GRL	97	97	97.25
Liverpool, Alder Hey Children's Hospital	ACH	95.25	94	96.25
London, Evelina London Children's Hospital for Sick Children	GUY	99.25	99.25	99.5
London, Great Ormond Street Hospital for Children	GOS	97	97.25	96.65
London, Harley Street Clinic	HSC	95.5	95.5	93.5
London, Royal Brompton & Harefield Hospital	NHB	99.25	99.5	98.75
Newcastle, Freeman Hospital	FRE	97.5	98.5	97
Southampton, Wessex Cardiothoracic Centre	SGH	95.75	98	93

DQI% for 16/17 data based on the 20 case note review May-Jun and Oct -Nov 2017				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Belfast Royal Victoria	RVB	94.5	96.25	94
Birmingham Children's Hospital	BCH	99.5	100	99.5
Bristol Royal Hospital for Children	BRC	98.75	99.25	98
Dublin, Our Lady's Children's Hospital	OLS	97	96.75	97.5
Glasgow Royal Hospital for Sick Children	RHS	99.25	99.25	99.75
Leeds General Infirmary	LGI	98	99	97.5
Leicester, Glenfield Hospital	GRL	97.25	94	98
Liverpool, Alder Hey Childrens Hospital	ACH	97.5	97	99
London, Evelina London Children's Hospital for Sick Children	GUY	96	94.75	97
London, Great Ormond Street Hospital for Children	GOS	99.5	99.75	98.75
London, Harley Street Clinic	HSC	95.75	97.75	93.25
London, Royal Brompton & Harefield Hospital	NHB	99.25	99.25	98.75
Newcastle, Freeman Hospital	FRE	99	98.25	99
Southampton, Wessex Cardiothoracic Centre	SGH	99	99.25	99

Table 6b ACHD Hospitals that received on site validation visits

DQI% for 14/15 data based on the 20 case note review May 15 - Feb 16				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Birmingham, Queen Elizabeth Hospital	QEB	79	77	87.5
Glasgow, Golden Jubilee Hospital	GJH	94.5	95.25	94
London, University College/St Bartholomew's Hospital	UCL	94.25	93.5	95.25
Manchester Royal Infirmary	MRI	97	97.25	96

DQI% for 15/16 data based on the 20 case note review May-Nov 2016				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Birmingham, Queen Elizabeth Hospital	QEB	75.25	66.75	89.75
Glasgow, Golden Jubilee Hospital	GJH	92.5	93.25	92
London, University College/St Bartholomew's Hospital	UCL/SBH	93.25	91.75	93.75
Manchester Royal Infirmary	MRI	97.7	97	96.75

DQI% for 16/17 data based on the 20 case note review May-Jun and Oct -Nov 2017				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Birmingham, Queen Elizabeth Hospital	QEB	92.5	89.75	95.5
Glasgow, Golden Jubilee Hospital	GJH	99	99	99
London, University College/St Bartholomew's Hospital	UCL/SBH	96.75	97.75	96
Manchester Royal Infirmary	MRI	98.5	98	98

Table 6c ACHD centres that undertook remote validation (or were non-participants)

DQI% for 14/15 data based on the 20 case note review May 15 - Feb 16				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Basildon, Essex Cardiothoracic Centre	BAS	Remote validation		
Blackpool Victoria Hospital	VIC	Remote validation		
Bristol Spire Hospital	GHB	Remote validation		
Brighton, Royal Sussex County Hospital	RSC	Remote validation		
Cambridge, Papworth Hospital	PAP	Did not Participate		
Cardiff, University Hospital of Wales	UHW	Remote validation		
Liverpool Heart & Chest Hospital	BHL	Remote validation		

DQI% for 15/16 data based on the 20 case note review May-Nov 2016				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Basildon, Essex Cardiothoracic Centre	BAS	Remote validation		
Blackpool Victoria Hospital	VIC	Remote validation		
Bristol Spire Hospital	GHB	Did Not Participate		
Brighton, Royal Sussex County Hospital	RSC	Remote validation		
Cambridge, Papworth Hospital*	PAP	83.5	84	82.5
Cardiff, University Hospital of Wales	UHW	Remote validation		
Liverpool Heart & Chest Hospital	BHL	Remote validation		

DQI% for 16/17 data based on the 20 case note review May-Jun and Oct -Nov 2017				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
Basildon, Essex Cardiothoracic Centre	BAS	Remote validation		
Blackpool Victoria Hospital	VIC	Remote validation		
Bristol Spire Hospital	GHB	Did Not Participate		
Brighton, Royal Sussex County Hospital	RSC	Remote validation		
Cambridge, Papworth Hospital	PAP	Did Not Participate		
Cardiff, University Hospital of Wales	UHW	Remote validation		
Liverpool Heart & Chest Hospital	BHL	Remote validation		

DQI% for 14/15 data based on the 20 case note review May 15 - Feb 16				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
London, Hammersmith Hospital	HAM	Remote validation		
London, Kings College Hospital	KCH	Remote validation		
London, St Georges Hospital	GEO	Remote validation		
Nottingham City Hospital	CHN	Remote validation		
Sheffield, Northern General Hospital	NGS	Remote validation		
Oxford, John Radcliffe Hospital	RAD	Remote validation		
Stoke, University Hospital of North Staffordshire	STO	Remote validation		
Wolverhampton Heart & Chest Hospital	NCR	Remote validation		

DQI% for 15/16 data based on the 20 case note review May-Nov 2016				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
London, Hammersmith Hospital	HAM	Remote validation		
London, Kings College Hospital	KCH	Remote validation		
London, St Georges Hospital	GEO	Remote validation		
Nottingham City Hospital	CHN	Remote validation		
Sheffield, Northern General Hospital	NGS	Remote validation		
Oxford, John Radcliffe Hospital	RAD	Remote validation		
Stoke, University Hospital of North Staffordshire	STO	Remote validation		
Wolverhampton Heart & Chest Hospital	NCR	Remote validation		

DQI% for 16/17 data based on the 20 case note review May-Jun and Oct -Nov 2017				
Hospital	**Hospital code**	**Overall DQI %**	**DQI for Surgery case notes seen**	**DQI for Catheter Procedure case notes seen**
London, Hammersmith Hospital	HAM	Remote validation		
London, Kings College Hospital	KCH	Remote validation		
London, St Georges Hospital	GEO	Remote validation		
Nottingham City Hospital	CHN	Remote validation		
Sheffield, Northern General Hospital	NGS	Remote validation		
Oxford, John Radcliffe Hospital	RAD	Remote validation		
Stoke, University Hospital of North Staffordshire	STO	Remote validation		
Wolverhampton Heart & Chest Hospital	NCR	Remote validation		

** Cambridge, Papworth Hospital participated in site validation for year 2015/16 only.*

Note: *No DQI is calculated for small hospitals that do not receive an external validation visit as no case notes are reviewed. The DQI is based on case note review.*
Note: *No ACHD is currently received from Republic of Ireland (ROI).*

These results are fed into the congenital heart services Specialised Services Quality Dashboard for monitoring outcomes in England and Wales by the Congenital Heart Services Clinical Reference Group, as are the overall number of complications within 30 days of procedures.

4.2 FUTURE CHALLENGES FOR QUALITY IMPROVEMENT BASED ON CONGENITAL HEART DISEASE OUTCOMES:

- To investigate other aspects of post-procedural care including complication rates and the need for unplanned additional procedures using recently accumulated data following procedures undertaken in the 2015-18 three-year cycle. These results will allow drilling down to individual complications and linkage to specific procedures.
- To understand why some centres might get statistically better results than other centres and then to help spread the necessary learning to allow all patients to be provided with uniformly good treatment.
- To focus on adult congenital heart disease outcomes. Although mortality rates for adult congenital heart disease patients remain very low, there is a need to develop a risk stratification model which accounts for factors or comorbidities which are specific to adult patients. From April 2015, the NCHDA dataset was updated with new fields to support the eventual development of such a model, including pre-procedural systemic and subpulmonary ventricular function, pre-procedural New York Heart Association functional class, smoking status and diabetes status, as well as evidence of pre-procedural ischaemic heart disease or pulmonary disease. We expect to publish data on these new fields after the first three-year cycle has completed in our 2015-18 report. Next year, we hope to explore the utility of the published Society of Thoracic Surgeons risk model for outcomes of patients with adult congenital heart disease.

5 RECOMMENDATIONS

- **Hospitals undertaking congenital cardiac surgery should work with specialist commissioners and aim to meet the NHS England Standards for the number of surgeons and associated volume of surgical activity.**
- **Commissioners and providers of obstetric services with the support of tertiary centre fetal cardiologists should ensure that there is access to training and appropriate equipment for sonographers to support the pre-natal detection of congenital heart conditions.**

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