National Congenital Heart Disease Audit Report

On

Data Quality of Procedures for CONGENITAL HEART DISEASE

For April 2024 – March 2025

At

University Bristol Hospitals NHS Foundation Trust (BRC)

3 June 2025

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Summary

A total of 1205 procedures were included in the BRC data return to NCHDA for the year April – March 2024-25 harvested on 12 May 2024. These comprised (413 Surgery, 779 Catheters, 13 others, 13 deaths within 30 days of a procedure) for the year 2023/2024 that were undertaken. These numbers include adult congenital procedures carried out at Bristol Heart Institute (BHI).

Following review of the Bluespier catheter laboratory and operating room activity log on the day of the validation visit, no additional procedures were identified that may be suitable for submission to the Registry.

This validation visit has been funded by the University Hospitals Bristol NHS Foundation Trust. Bristol Royal Children's Hospital (BRC) is part of the UHBristol NHS Foundation Trust and was undertaken in a remote format at the Trust request. Neither the external clinician or NCHDA Clinical Audit nusre

BRC have had a dedicated congenital cardiac information team since 2014. There are 4 individuals who provide 2.3WTE

- Information Analyst & Clinical Data Manager band 6 (25.5 hpw)
- Cardiac Data Manager band 5 (15 hpw)
- Cardiac Data Manager band 5 (37.5 hpw)
- Congenital Cardiac Clinical Data Reviewer band 5 (11.5 hpw)

It should be noted that it is a recommended standard in the New Congenital Heart Disease Review (NHSE July 2016) Recommendations number B32(L1) that states there should be a minimum of 1.0 WTE dedicated Level 1 paediatric cardiac surgery/cardiology data collection manager and 1.0WTE assistant paediatric cardiac surgery/cardiology data collection manager; and Recommendation (B33 (L1) states that there should be 1.0WTE data manager for Level 1 ACHD services.

Real time data input by all clinicians is encouraged at BRC and is mostly undertaken using the HeartSuite cardiac information system. This is a standalone database and uses the International Paediatric and Congenital Cardiac Code (IPCCC) Long List of clinical codes. NCHDA uses the Short List that is derived from the IPCCC Long List. HeartSuite has built in mapping intended to match codes used in the Long List to codes used in the NCHDA Short List at the time of submission.

The Reviewers are grateful to the Clinical Director who made the time to briefly connect with them at the end of the day during a busy outreach clinic.

Patient Consent for External Validation of Hospital Notes

Under the General Data Protection Regulation (GDPR) of May 2018, it is expected that patients will be made aware by all Organisations who care for them and produce data relating to their medical conditions to be open and transparent about how their data is being kept, used and who it is being shared with and how it may be disposed of. As such, NCHDA now no longer require individual patient informed consent.

Data Quality Indicator (DQI)

The DQI for the Trust is calculated to be (with the previous year in parentheses) **99.5%** (99.75, 99.75, 99.75,) with domain scores Demographics 1.0 (1.0, 1.0) Pre Procedure .99 (.99, 1.0, .99,) Procedure 1.0 (1.0, .99, 1.0) and Outcome .99 (1.0, 1.0, 1.0).

There were 3 discrepancies in a total of 1015 variables across 20 patients who underwent 26 therapeutic procedures (12 catheter interventions, 14 operations).

Separate DQI for Catheters and Surgery

Since the 2009 cycle of visits commenced, as well as the overall DQI for each centre, the DQI for surgery and catheters is being calculated. It is recommended that a minimum number of 5 procedures in either group are required for the differential DQI calculation.

Year	Data Year Validated	Surgery DQI	Catheter DQI
2014	13/14	98.25%	93.25%
2015	14/15	95%	94%
2016	15/16	99.25%	98.25
2017	16/17	99.25%	98%
2018	17/18	99.25%	99%
2019	18/19	98.75%	99.8%
2020	19/20	100%	99%
2021	20/21	98.75%	100%
2022	21/22	100%	99.75%
2023	22/23	99.75%	99.75%
2024	23/24	99.75%	99.75%
2025	24/25	99.75%	99.75%

The body of this report is drawn from answers given on the NCHDA pre visit questionnaire and from discussions on the day of the visit.

Actions or changes undertaken since 2024 Validation Visit:

1. The data collection Standard Operating Protocols (SOPs)s are in place for both the paediatric and ACHD services. They are regularly reviewed. The Cardiac Data Team made monthly uploads to NCHDA in 24-25.

2. It is reported that the electronic activity log for the operating rooms (BlueSpier) now has OPCS 4.6 coding active.

3. One cardiac data manager role has been rebanded from A4C Band 4 to AFC Band 5.

Digital Maturity (electronic health records) in 2025.

There is no single unified digital health record system that allows users to see **all** of the patient data in one system and there are still some paper records kept such as observation charts, clinic notes etc at point of care.

It is reported that paper documents get scanned after the clinic /admission into the electronic patient record system (Evolve). Evolve is a Medical Record platform supporting digital maturity programmes through removal of paper from the care process. It is provided as a fully managed service, delivered securely using Microsoft Azure's cloud.

In the cath labs, electronic activity records are stored in a system known as CCW and BlueSpier is also used. There are paper bound log books in the paediatric cath labs also. As stated elsewhere, BlueSpier digital activity documenting is used in all operating rooms and was provided for the case ascertainment part of this validation.

NCHDA data are input to HeartSuite, as described elsewhere, is a standalone information collection database and when validated locally are submitted to the NCHDA registry.

It is reported that for the complete NCHDA dataset data to be collected between 2 and 7 applications (each with unique user id and password control) may have to be accessed.

Introduction

Prior to the validation visit the combined NCHDA return from the cardiac department of Bristol Royal Hospital for Children and Bristol Royal Infirmary indicated that1205 procedures were included in the BRC data return to NCHDA for the year April – March 2024-25 harvested on 12 May 2024. These comprised (413 Surgery, 779 Catheters, 13 others, 13 deaths within 30 days of a procedure) for the year 2023/2024 that were undertaken. As stated above, these numbers include adult congenital procedures carried out at Bristol Heart Institute (BHI).

20 Sample sets of case notes were selected for review on each day. A Reserve list of 10 was also supplied by NCHDA in case any of the first 20 were irretrievable. On the day nil records were required from the Reserve list to replace those that were unavailable from the Sample. The accuracy of the NCHDA data return was then checked against each set of notes on each day.

One external Consultant in Congenital Cardiology undertook the validation visit at Bristol Royal Children's Hospital with the NCHDA Clinical Data Auditor. This visit was conducted remotely via MS Teams at the request of BRC.

Review of the notes

BRC is still in the process of moving towards 'paperless' hospital record keeping. This involves having a paper copy of patient's notes only during an in-patient admission or an outpatient appointment. On discharge or completion of the episode the patient's notes are immediately scanned onto an electronic patient record system 'Evolve'. The process of scanning all historical patient notes is now established in the paediatric cardiac service and usually there are no significant delays reported with notes being scanned. In the Bristol Heart Institute (BHI) there are occasional delays related to the scanning of adult patient notes which sometimes results in delayed upload of certain records to NCHDA.

The electronic patient record (ePR) is known as CareFlow and Evolve. Evolve is the main document repository receiving reports and images from other databases or applications. The hospital case notes seen on the day of the validation visit, were digital images compiled from the ePR into folders for each patient. On the whole, the images were very tidy, very good quality and made up of very few scans of traditional paper bound documents. The pages that were required to be seen by the Reviewers, although sometimes a little small, had been meticulously ordered and at times the transition between the various hosts screens was slow and clunky.

1. The Joint Clinical Conference (JCC) discussion sheets were seen in most of the case notes.
2. As previously reported, the cardiac catheter procedure sheet was easy to read and well laid out. Images of the labels from implantable devices were shown.

3. Operation notes were likewise very clearly set out, and scans of the hand written procedure notes were seen. Occasionally the handwritten notes were very difficult to decipher.
4. The transfer from OR to PICU document that would confirm whether or not a patient had been extubated in theatre was useful but did not always appear to be present in the digital images that had been collected.
5. Specific documentation of the date and time of extubation did not always appear to be clearly noted and this was then seen on the PICU digital documentation where available.
6. 1 record appears to have been coded with an inherited cardiac condition (ICC) due to a technical mapping error between the Long and Short Codes and this had not been corrected on reverse validation.
7. As previously reported, the images of the PICU discharge summaries were very detailed and therefore extremely helpful in validating the perioperative data fields.
8. In the discharge summaries of ACHD patients it was difficult at times to find the detail of the timeline of actions and interventions of an episode.
9. As previously reported, NYHA status did not appear to be routinely recorded in the hospital records of patients aged over 16 at admission clerking or outpatient pre admission appointments. The specific proforma created and available for the ACHD risk data appeared to be variably completed. These fields are part of specific pre procedure risk assessment used in the NCHDA ACHD dataset.

Validation of Deceased Patients Diagnostic and Procedure Coding

Commencing with the validation of the 2013/14 data, the National Congenital Heart Disease Audit will request to verify any dates of death of deceased patients included in the year under review. The diagnosis and procedure coding along with the Partial Risk Adjustment in Surgery (PRAiS) fields will also be validated. 13 deaths occurred within 30 days of a therapeutic catheter or surgical procedure and these case notes were examined in closer detail. The PRAiS sensitive fields (demographics, diagnosis, previous procedures, comorbidities and procedure performed) were reviewed for each of the patients and the findings were:

- All dates of death were correct
- 1 record appears to have an important diagnostic code absent
- It was easier to find documentation or confirmation of whether or not there had been a discussion with the Medical Examiner or Coroner after a patients death.
- Medical certificates of cause of death (MCCD) were not routinely see.
- The Medical Examiners office documentation seen appears to have clearly designed fields to record whether or not a death has been discussed with or referred to Coroner and decisions made.

As reported since 2023, an annual query is run to compare life status on NHSE Summary Care Record with known NCHDA patients as a further check for individuals who may have died post discharge.

Log Book Check for full NCHDA case ascertainment

The Bluespier theatre booking application is now used across all operating rooms and cathlabs at UHB NHS Trust. It is not clear whether or not this application is considered a 'gold standard' of activity or how this information collected is used. The Reviewers were informed that OPCS coding is used in this application but this was not shared at this visit. OPCS coding should not be solely relied to identify congenital patients as the numbers of codes available are quite limited.

The data for operating rooms and cath labs were initially displayed all together which is not very helpful when checking case ascertainment for separate catheter and operating procedures. This was adjusted by the host team to enable this part of the validation to be performed.

Review of the Activity Theatre Log

The activity log from BRC operating theatres and one Hybrid room were made available. BRI theatres 1, 2, 9 and hybrid were offered for review. Also included in the Bluespier extract was the activity for operating rooms 3 and 5 (paediatric).

1. 4 submitted records were not validated

Review of the Cath Lab Activity Log at BRC/BRI

There is 1 paediatric catheter laboratory at BRC and 5 catheter laboratories at BRI. All activity appears to be recorded in Bluespier.

- 16 submitted records were not validated. This may be because they were procedures that were performed in another place such as PICU or NICU.

Pre Visit Questionnaire

The Congenital NICOR pre visit Questionnaire was completed and returned prior to the validation visit. This confirmed that there are good processes and procedures in place in regard to:

Data Security and Management
Validation and Quality Assurance
Training in Data Management
Information Governance Training
There is or are identified accountable person/people for NCHDA data quality and information validity
Data Submissions are Timely and Accurate

Data Quality Indicator Assessment:

20 Patients who had 26 Procedures – 12 Caths and 14 operations.

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		9	11
2	NHS Number	20	20		9	11
3	Surname	20	20		9	11
4	First Name	20	20		9	11
5	Sex	20	20		9	11
6	DOB	20	20		9	11
7	Ethnicity	20	20		9	11
8	Patient Status	20	20		9	11
9	Postcode	20	20		9	11
10	Pre Procedure Diagnosis	24	26	2 incorrect	10/12	14
11	Previous Procedures	63	63		30	33
12	Patients Weight at Operation	26	26		12	14
13	Height	26	26		12	14
14	Ante Natal Diagnosis	1	1		-	1
15	Pre Proc Seizures	26	26		12	14
16	Pre Proc NYHA	9	9		6	3
17	Pre Proc Smoker	9	9		6	3
18	Pre Proc Diabetes	9	9		6	3
19	Hx Pulmonary Dis	9	9		6	3
20	Pre Proc IHD	9	9		6	3
21	Comorbidity Present	26	26		12	14
22	Comorbid Conditions	39	39		15	24
23	Pre Proc Systemic Ventricular EF	26	26		12	14
24	Pre Proc Sub Pul Ventricular EF	24	24		12	12
25	Pre-proc valve/septal defect/ vessel size	7	7		7	-
26	Consultant	26	26		12	14

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
27	Date of Procedure + Time Start	26	26		12	14
28	Proc Urgency	26	26		12	14
29	Unplanned Proc	2	2		-	2
30	Single Operator	4	4		4	-
31	Operator 1	26	26		12	14
32	Operator 1 Grade	26	26		12	14
33	Operator 2	22	22		8	14
34	Operator 2 Grade	22	22		8	14
35	Procedure Type	26	26		12	14
36	Sternotomy Sequence	14	14		-	14
37	Operation Performed	26	26		12	14
38	Sizing balloon used for septal defect	2	2		2	-
39	No of stents or coils	2	2		2	-
40	Device Manufacturer	7	7		6	1
41	Device Model	7	7		6	1
42	Device Ser No	7	7		6	1
43	Device Size	5	5		4	1
44	Total Bypass Time	14	14		-	14
45	XClamp Time,	11	11		-	11
46	Total Arrest	2	2		-	2
47	Cath Proc Time,	12	12		12	-
48	Cath Fluro Time,	12	12		12	-
49	Cath Fluro Dose,	12	12		12	-

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
50	Duration of Post Op Intubation	10	10		-	10
51	Post Procedure Seizures	26	26		12	14
52	Post Proc Complications	8	8		-	8
53	Date of Discharge	25	26	1 incorrect	12	13/14
54	Date of Death	-	-		-	-
55	Attribution of Death	-	-		-	-
56	Status at Discharge	26	26		12	14
57	Discharge Destination	26	26		12	14

The Overall Trust DQI = 99.5% Cardiology DQI = 99.75% Surgery DQI = 99.75%

This DQI is based upon the domain scoring below. The methodology for this DQI is provided in the paper The CCAD Audit – An Introduction to the Process.

DOMAIN	DOMAIN Score	
Demographics Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status,	**Overall 1.0.**	
	Card 1.0	**Surg** 1.0
Pre Procedure Pre procedure Diagnosis, Selected Previous Procedures, Patient Weight at Operation, Consultant, Antenatal Diagnosis, Pre Procedure Seizures, Comorbid Conditions, **Height, Pre Procedure NYHA, Pre Procedure Smoker, Pre Procedure Diabetes, Previous Pulmonary Disease, Pre Procedure Ischaemic Heart Disease, Comorbidity Present, Pre Procedure Systemic Ventricular Ejection Fraction, Pre Procedure Sub Pulmonary Ejection Fraction, Pre Procedure valve/septal defect/vessel size,** Note, the scores for his domain are affected by the selected previous procedure and pre procedure diagnosis	**Overall .99**	
	Card .99	**Surg** 1.0
Procedure Date of procedure, Operator 1, Operator 2 Cardiopulmonary Bypass used, Operator 1 grade, Operator 2 grade, Operation performed, Sternotomy sequence, Bypass Time, CircArrest, XClamp Time, Cath Proc Time, Cath Fluro Time, Cath Fluro Dose, **Time Start, Procedure Urgency, Unplanned Procedure, Single Operator, Sizing Balloon Used, No of Stents/Coils, Device Mfr, Device Model, Device Ser No, Device Size,**	**Overall 1.0**	
	Card 1.0	**Surg** 1.0
Outcome Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination. **Post Procedure Complications.**	**Overall** .99	
	Card 1.0	**Surg** .99

Data Quality Indicator Assessment

The Trust DQI = 99.5%

This DQI is based upon the domain scoring below. The methodology for this DQI is provided in the paper The NCHDA CCAD Audit – An Introduction to the Process.

DOMAINS	2022 21/22	2023 22/23	2024 23/24	2025 24/25
Demographics	1.0	1.0	1.0	1.0
Pre Procedure	.99	1.0	.99	.99
Procedure	1.0	.99	1.0	1.0
Outcome	1.0	1.0	1.0	.99

Conclusions

On the whole the NCHDA data are accurate, well documented, good quality and were appropriately recorded in the Theatre and Cath Lab logs that were seen for BRC. The digital case note files for each patient were well put together and fairly easy to follow.

The Data Quality Indicator Score for this validation visit has remained excellent at 99%+. Well done. The DQI score is also now included in the NHSE CQINs quarterly dashboards for congenital heart disease.

The Trust allowed a decrease the 0.2WTE in the congenital cardiac team information team in 2022 and this remains unaddressed. The Centre does not therefore meet the recommended standard in the New Congenital Heart Disease Review (NHSE July 2016) Recommendations number B32(L1) that states there should be a minimum of 1.0 WTE dedicated Level 1 paediatric cardiac surgery/cardiology data collection manager and 1.0WTE assistant paediatric cardiac surgery/cardiology data collection manager; and Recommendation (B33 (L1) states that there should be 1.0WTE data manager for Level 1 ACHD services.

As reported elsewhere while the Reviewers note that there are 4 individuals in post covering 2.3WTEs to support all of congenital heart disease data collection, just one of these individuals (0.3WTE) has a clinical background.

The Reviewers are grateful the Clinical Director who did connect to the validation via MS Teams very briefly. This was the only clinician who did so.

It is helpful for local colleagues both to understand the process of the case note review in general and also to appreciate the accessibility in reverse of their own data systems. Particularly for the people doing procedures and entering the data its quite informative for them to be present for some part of this external review. It also very much helps the Reviewers to have some local colleagues around when looking through the notes even when they have been well digitally collated and marked up by the DBMs.

As reported elsewhere, this validation was undertaken entirely remotely at the request of the NHS Trust. It is the conclusion of the Reviewers that this was not completely satisfactory. The movement between different slides showing the information was occasionally ‘clunky’ as the different data managers interchanged shared screens. As reported in the Previsit Questionnaire Survey by BRC, between 4 – 7 data applications may need to be accessed in order to collect the NCHDA date prior to submission. There was a complete absence of host clinicians interaction during any part of the review until the Clinical Director, while at an out reach clinic in another city, joined in very briefly at the end of the day between seeing two patients. In previous face to face validation visits there have been many individuals

who have participated in some part of the validation discussions or tasks throughout the day. Remote validation does not support senior trainees to gain experience and insight into the importance of accurate NCHDA coding, completion of quality checks of data and how that data is interpreted in NCHDA analyses.

Review of Deceased Patients case notes.

As stated above, all dates of death were found to be correct. The death summaries for paediatric patients were very informative. 1 record may have a coding discrepancy. There are processes in place to capture out of hospital deaths for this patient cohort.

Recommendations

1. Active consideration of appointing a further 1.0WTE dedicated data manager for the NCHDA adult congenital (ACHD) data.
2. It is recommended that the Standard Operating Protocols (SOPs) for the congenital data collection, (paediatrics and ACHD), continue to be reviewed to ensure that they include detailed guidance on and **exactly who** is responsible (and in what timeframe) for;
   i. Input of the data for each procedure and at which point of the service delivery
   ii. Where hand written notes are created, that these are specific to the procedure and easily decipherable.
   iii. Validity checking and completeness and the time intervals for feedback to responsible clinicians on this with a clear time scale and line of responsibility for rectifying any omissions or errors in both surgery and cardiology disciplines
   iv. Leading the local review (and how frequently and in which forum for both disciplines)
   v. Making timely submissions (monthly is required) as NICOR are now commissioned by NHSE to report each month all activity within 2 weeks of discharge where possible.
   vi. Timely reverse validation of the data submitted to NCHDA with all relevant clinicians
   vii. Monthly to quarterly PRAiS analysis as required as this analysis co-informs the NHSE CQINs quarterly dashboard activity data.
   viii. Ensuring that relevant case and procedural records and logs are extracted, sorted and printed from electronic sources (HeartSuite, Evolve, Bluespier etc) in advance to be easily accessible by the Auditors on the day of the visit.
   ix. Identifying the responsible clinician for completing the field for Attribution of Death as this is not a non clinical DBMs responsibility.
   x. Checking for any out of hospital deaths that may have occurred in the congenital cohort.
3. It is recommended that the next NCHDA validation visit should be in the face to face format for both external clinician and the Clinical Audit Nurse as this will encourage greater local clinician input and will offer a Specialty Trainee experience in this national registry output.
4. As recommended in 2011-24, it is suggested that consideration be given to mandatory identification of congenital procedures in the BRI electronic theatre logs as the entries are made. Precise, specific congenital diagnosis descriptions would be very helpful in this application.
5. Entries to the cath lab or operating information system should continue to be reviewed monthly and if necessary staff given extra training to more specifically describe procedures performed and how to identify patients with adult congenital heart disease rather than inherited heart disease. Shortening of names of procedures should always be avoided as this may lead to mis interpretation. The use of recognised clinical coding such as OPCS4.6, ICD10/11 while encouraged should be used with the caution that the coding for congenital heart disease is still

quite sparse in these libraries. IPCCC codes are a preferred coding system as this is highly accurate when all users are appropriately trained.

6. It is recommended that if Bluespier operating theatre management system is a 'gold standard reference point' for all catheter lab and operating room activity, that it is regularly scrutinized for completeness and accuracy against the NCHDA data submissions.
7. It is also recommended that the DBMs should visit with other centres that send congenital cardiac data to NCHDA.
8. It is recommended that regular, training sessions and updates for all staff who may be involved with data input and should continue to be part of the induction process for new staff. This should include adult congenital staff members, who may be working solely within the BRI. HeartSuite Training should include information on the difference of the IPCCC Long Codes and how they are mapped to the Short List codes that NCHDA uses.
9. It is recommended that ST6's and above are encouraged to volunteer to assist with a NCHDA site validation visit.