The National Congenital Heart Disease Audit

Procedures for CONGENITAL HEART DISEASE

Data Quality Audit for April 2024 to March 2025

Birmingham Children's Hospital NHS Foundation Trust

15 July 2025

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Summary

Prior to this validation visit the Congenital NICOR data return from the Birmingham Children's Hospital NHS Foundation Trust (BCH) indicated that some 827 (surgery 353, catheter 440, others 34, [deaths 8/16 within 30 days of a Specific Procedure]) procedures had been undertaken during the data collection year of 2024/2025 on children with congenital heart disease. Following review of the catheter laboratory and operating room activity logs on the day of the validation visit, no additional procedures were identified.

20 sets of hospital case notes are randomly selected from the BCH submission (the Sample) with a further 10 randomly selected as reserves. 3 case notes were used from the reserve list to replace those unavailable in the Sample. A combined total of 26 procedures were reviewed, 12 catheters and 14 operations.

The HeartSuite information system continues to be used at Birmingham Children's Hospital to collect and manage all congenital cardiac data for this year under review and for the year 25/26. The Trust is currently launching EPIC, an over arching clinical medical and patient information system that can be used throughout all specialties within the organisation and community health service. The 'go live' date was 15 May 2025. Paediatric Cardiology went 'live' on with a basic EPIC module and the Cupid module that is specifically for cardiology is expected in April 2026.

This validation visit has been fully funded by the Birmingham Women's and Children's NHS Foundation NHS Trust. This visit was supported on site in person by Dr A Deri, Consultant Congenital Cardiologist from Leeds and the NCHDA Clinical Audit Nurse.

BCH Overview

There is a 1.0WTE overall Cardiac Information Manager (IM) at BCH. The current IM was appointed in November 2020. There are a further 1.6WTEs supporting the cardiac information collection.

Actions taken since the 2024 Validation Visit:

- As previously reported, there are monthly meetings with Catheter and Surgical leads to check and validate the previous months data. This helps with the on-going checking of coding accuracy, completeness and inclusion of complications.
- Refresher training takes place for cardiac interventionists and Registrars highlighting the key fields that are sometimes missed in order to try and eliminate any missing data.
- Post validation visit information is presented at the Cardiac Audit meeting, where any issues found are raised and discussed in the meeting (open forum).
- The Reviewers were made aware that there has been a sudden and unexpected loss of 0.5WTE clinical colleague (CNS) who supported the NCHDA registry and the cardiac information department as a whole.

Data Quality Indicator

The DQI score for BCH is **99.5%** (99.6, 99.5, 99.5) The domain scores are; Demographics 1.0 (1.0, 1.0, 1.0), Pre Procedure .98 (.99, .985, .99), Procedure 1.0 (.996, .997, 1.0), and Outcome 1.0 (1.0, 1.0, 1.0).

This represents another excellent DQI score. Well done.

There were 5 discrepancies in 853 data variables. This represents another excellent DQI score and confirms that there are strong checks and balances in place at BCH to ensure good quality validated data is collected and submitted to NCHDA.

Separate DQI for Surgery and Catheters

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.

DQI	Data Year Reviewed	Surgery	Catheters
2015	2014-15	98.5%	98%
2016	2015-16	98.75%	96.75%
2017	2016-17	100%	99.5%
2018	2017-18	98.75%	99%
2019	2018-19	99.5%	98.5%
2020	2019-20	99%	99%
2021	2020-21	99.75%	99.5%
2022	2021-22	99.25%	99.5%
2023	2022-23	100%	99%
2024	2023-24	99.75%	99.75%
2025	2024-25	99.75%	99.25%
2025	2024-25	99.75%	99.25%

The NCHDA 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 Maturity in 2025

This Trust now has a brand new single unified digital health record system allowing **all** of the patient data to be seen in one system, EPIC. As stated elsewhere, EPIC is an overarching patient information system that encapsulates all hospital and community care.

At the time of this visit in 2025, perfusion records are the only documents that are still kept in paper format and on EPIC. Also at the time of this validation visit, the move from HeartSuite where all NCHDA data had been kept and EPIC being commissioned overlapped. So there were 2 separate user logins required to capture all NCHDA data.

Currently the version of EPIC at BCH is not configured to the CUPID module requirements to collate data for NCHDA. Therefore, all documentation and primary data is completed on EPIC, then the audit team have to transcribe it over to Heartsuite so that the correct IPCC codes are used. Then the data can be extracted in the correct format for uploading to QREG5.

It was also brought to the Reviewers attention that there is no time line for EPIC to receive the archived data of over 20+ years that is currently held in HeartSuite.

Introduction

As stated above, the NCHDA data return, prior to checking the theatre and catheter lab log books, indicated that the combined cardiac departments of the Birmingham Children's Hospital have undertaken some 827 (surgery 353, catheter 440, others 34, [deaths 8/16 within 30 days of a Specific Procedure]) procedures had been undertaken during the data collection year of 2024/2025.

The Information Manager in collaboration with colleagues completed the pre visit self assessment questionnaire at BCH.

The accuracy of the NCHDA data return was then checked against each set of randomly selected patients hospital notes to enable the Data Quality Indicator (DQI) to be scored.

Review of notes

1. The paper hospital notes had again been meticulously prepared by the Congenital Audit Team
2. The relevant clinical records were highlighted in the case notes with post it notes, and therefore very easy to find
3. The NHS number was always easily available on the individual patients labels.
4. As previously reported, consistent documentation of ventricular function still needs to be improved and the Reviewers had to search through the hospital notes on occasions to validate these data.
5. Also as previously, it was difficult to find a concise and succinct list of a patients comorbidities. Sometimes these were documented over several entries but not all together in a concise list.
6. Precise documentation of the exact time and date of ET tube extubation was sometimes challenging to find in the hospital notes.

Review of Log Books for Operating Rooms and Cardiac Catheter

Paper log books have not been kept at BCH for over a decade and have been replaced by Operating Room Information System (ORMIS) in both the cath labs and operating theatres. A spreadsheet of all cases ordered by date in the operating room and the cath labs for the period under review was provided on a screen for the visiting clinician to review.

The findings were:

1. 0 records were identified that may be suitable for inclusion in NCHDA

Validation of Dates of Death and Procedure Coding of Deceased Patients

This commenced with the validation of the 2014/15 data. The NCHDA wish to verify any dates of death of deceased patients included in the year under review. The diagnosis and procedure coding will also be validated.

BCH identify out of hospital deaths either from the local information system as its updated and/or from running regular queries on the NHSE Strategic Tracking Service (NHS Spine). For non NHS patients or patients from Scotland or N Ireland, the Information Team liaise with those colleagues as required.

8 deceased patients were identified in the data return for 2024-25 who had died within 30 days of their therapeutic procedure. The PRAiS sensitive fields were reviewed for each of the patients and the findings were:

- All data were found to be correct
- 2 records may have discrepancies in the Comorbidity field
- 1 record may have a discrepancy in the Attribution of Death field
- No MCCD death certificates were seen

It was reported to the Reviewers that currently Mortality and Morbidity (M+M) meetings are suspended as EPIC eHR has not been adapted to record the data from this forum as the data on deceased patients whose date of death was prior to 15 May 2025 is not yet available in the eHR.

It was expected that M+M meetings would recommence in August.

Casenote Audit

	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	24		12	14
11	Previous Procedures	40	40		20	20
12	Patients Weight at Operation	26	26		12	14
13	Height	25	25		11	14
14	Ante Natal Diagnosis	4	5	1 incorrect	-	4/5
15	Pre Proc Seizures	26	26		12	14
16	Pre Proc NYHA	-	-		-	-
17	Pre Proc Smoker	-	-		-	-
18	Pre Proc Diabetes	-	-		-	-
19	Hx Pulmonary Dis	-	-		-	-
20	Pre Proc IHD	-	-		-	-
21	Comorbidity Present	26	26		12	14
22	Comorbid Conditions	28	30	2 absent	12/13	16
23	Pre Proc Systemic Ventricular EF	25	26	1 unable to validate	11/12	14
24	Pre Proc Sub Pul Ventricular EF	20	21	1 unable to validate	10/11	10
25	Pre-proc valve/septal defect/ vessel size	6	6		6	-
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	-	-		-	-
30	Single Operator	-	-		-	-
31	Operator 1	26	26		12	13
32	Operator 1 Grade	26	26		12	13
33	Operator 2	26	26		12	14
34	Operator 2 Grade	26	26		12	14
35	Procedure Type	25	25		12	14
36	Sternotomy Sequence	14	14		-	14
37	Operation Performed	26	26		12	14
38	Sizing balloon used for septal defect	26	26		-	-
39	No of stents or coils	3	3		3	-
40	Device Manufacturer	9	9		8	1
41	Device Model	9	9		8	1
42	Device Ser No	9	9		8	1
43	Device Size	9	9		8	1
44	Total Bypass Time	11	11		-	11
45	XClamp Time,	11	11		-	11
46	Total Arrest	4	4		-	4
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	5	5		1	4
53	Date of Discharge	25	25		12	14
54	Date of Death	1	1		-	1
55	Attribution of Death	-	-		-	-
56	Status at Discharge	26	26		12	14
57	Discharge Destination	26	26		12	14

Data Quality Indicator Assessment:

The Overall Trust DQI = 99.5% Cardiology DQI = 99.25% Surgery DQI = 9.975%

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 .98**	
	Card .97	**Surg** .99
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** 1.0	
	Card 1.0	**Surg** 1.0

DOMAIN.	Score 2025	Score 2024	Score 2023	Score 2022
Demographic	1.0	1.0	1.0	1.0
Pre Procedure	.98	.99	.985	.99
Procedure	1.0	.996	.997	.99
Outcome	1.0	1.0	1.0	1.0

Conclusions

The NCHDA data were of very good quality. The Data Quality Indicator (DQI) has remained excellent at 99.5%. This also demonstrates that there are very robust processes in place to ensure good quality data standards are maintained.

As previously reported, it is very clear that BCH NHS Foundation Trust consider the matter of collecting good quality, accurate and validated information about patient procedural activity to be of the highest importance and this has become embedded within the culture in the Cardiac Department. There were just 5 discrepancies in 853 variables. The Validation Team would particularly like to recognise the level of conscientiousness displayed by the Cardiac Information Manager and colleagues in preparing the hospital notes and various printed sheets so meticulously. This is a very large task to perform.

Prior to May 2025 clinicians input much of the NCHDA data to HeartSuite in the first instance. This data input has now changed to EPIC. Only the basic module of EPIC has been launched in the first instance. There is a specific EPIC module named CUPID that collects data for the cardiac specialty including congenital heart disease. The non audit team who do not have any clinical qualifications have to then transcribe the data from the EPIC electronic health record (eHR) into HeartSuite as the CUPID module has not been made available. It is of concern that during this process, due to human error data could be mis transcribed, missed or lost entirely. It is of further concern that it appears that the EPIC suppliers may not have built, tested or integrated an abstraction tool either for the congenital data meaning that it is unlikely to be possible to submit NCHDA data directly from EPIC to the national database during the data collection year up to April 2026. Data for NCHDA should be submitted regularly, monthly is recommended and should be no more that 3 months in arrears.

Finding descriptions of ventricular function prior to procedures was improved this year but was challenging sometimes due to the vagueness of terms used. There was at times a little difficulty in finding clear, consistent and concise listing of a patient comorbidities. This is all required data for NCHDA.

As previously reported, the standard and accuracy of the information recorded in ORMIS for surgery appears to continue to improve since the 2014 visit, however it is still a little poor in places for the catheter procedures. It was a little difficult at times to clearly identify exactly what catheter procedure had actually been performed in some of the entries. This data is heavily reliant on the non clinical data managers being able to match a patient entry on ORMIS with a record in HeartSuite previously and now EPIC.

Within the review of the deceased patients data all dates of death were correct and there were a very small number of discrepancies identified. The discharge summaries for deceased patients were of good quality with details very clearly laid out and easy to follow.

BCH have confirmed that all inconsistencies raised at this visit have been internally reviewed and amended where appropriate.

Recommendations

1. It is recommended that Standard Operating Protocols (SOP) for the data collection, to include detailed guidance on and exactly who is responsible for each of the following be regularly reviewed to ensure they fit the correct purpose. IE;
    i. Ensuring each patient/parent/guardian is given appropriate information in relation to how their data are recorded, stored and who it is shared with in line with GDPR 2018.
    ii. Input of congenital patients NCHDA required dataset items and at which point of service delivery
    iii. Encouraging every responsible clinician or allied healthcare professional to input complete data for each operation, diagnostic or catheter intervention at the point of the service delivery from admission to discharge and to own their data.
    iv. Recording the knife to skin time for all surgical procedures where it can be validated (ie perfusion or anaesthetic record).
    v. Recording of date and time of extubation
    vi. 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
    vii. Reverse validation of the data submitted to NCHDA by responsible clinicians in conjunction with the Data/Audit Managers at least monthly.
    viii. Where possible, running the PRAiS 4.2 (Partial Risk Analysis in Surgery) analysis tool monthly. This will inform the quarterly NHSE Dashboard reports.
    ix. Ensuring that dates of death are reported for any BCH patient who has previously had a record submitted to the NCHDA
    x. Leading the local review (and how frequently and in which forum for both disciplines)
    xi. Making timely submissions (monthly is recommended where possible) and quarterly within 2 weeks of each quarter end is now mandated by NHSE.
    xii. Include all details of manufacturer, model and serial numbers of all implantable devices in the procedure record for each patient.
    xiii. Ensuring the date and time of discussions with either the local Medical Examiner or Coroner are clearly recorded in the hospital notes of deceased patients.
    xiv. Completion of the field for Attribution of Death is recommended during the Mortality and Morbidity meetings as this should not be a non clinical DBMs responsibility.

2. Urgently consider recruiting another 0.5WTE CNS from congenital cardiology to support the Cardiac Information Team as this has was proven to be of invaluable support to them.

3. In liaison with the person responsible for staff training and development in the Trust, to continue regular training/updates not only for the NCHDA Data Managers, but for all staff in the

Department who may be involved with data input and validation. This should include regular Quality Assurance and Governance training and visits to other centres who are involved in NCHDA data collection and submission.

4. As previously recommended, to consider developing a standard discharge summary style for use throughout the cardiac department. Such a document should logically list all NCHDA pertinent information to that in-patient episode and previous interventions or operations.
5. All trainees (ST6 and above) should be encouraged to volunteer to participate in a NCHDA site validation visit as an external colleague to gain insights to the importance of maintaining good standards in data collection and quality management.