The National Congenital Heart Disease Audit

Procedures for CONGENITAL HEART DISEASE

Data Quality Audit
For the year April – March 2024-25

Barts Health NHS Trust

Thursday 18 September 2025

performed by Lin Denne and Dr S Duignan

Summary

Prior to the theatre and cath lab logbook validation at this visit, the data submission to NCHDA from the department for Adult Congenital Heart Disease at Barts Health NHS Trust indicated that a total of 512 procedures (107 surgical, 405 catheter procedures, 0 others, and 3 deaths within 30 days of a specific procedure) were undertaken during the data collection year April 2024 to March 2025.

Following review of the catheter laboratory and operating room activity logs on the day of the validation visit, 48 additional procedures were identified and where found to be suitable were subsequently submitted to the Registry.

This validation visit has been fully funded by the Barts Health NHS Trust. The site visit was carried out on site in person by Dr S Duignan Specialty Trainee (ST8) in Congenital Cardiology from London and the NCHDA Audit Nurse.

In April 2015 The Heart Hospital cardiac unit moved to the St Bartholomew's' NHS foundation Trust site (SBH).

As previously reported, there are 9 consultant cardiologists at SBH that specialise or have an interest in adult congenital cardiology. There are 2 Congenital surgeons who undertake some Congenital cardiac operations at SBH and who also practice at Great Ormond Street Hospital for Children which is in an adjacent NHS Foundation Trust. There are 13 further cardiac surgeons from SBH who also do procedures on patients with congenital heart disease. Many of these appear to be part of the surgical aortic valvular service and account for 44 (41%) of the procedures submitted to NCHDA.

Also, as previously reported at SBH, there is a 1.0. WTE Senior Clinical Nurse Specialist (CNS) for the National Adult Cardiac Surgery Audit (NACSA) registry and a 1.0WTE supporting data manager/analyst. These 2 individuals also have full responsibility without any particular time ring fenced to collect manage and quality control, NCHDA data. For NCHDA this also involves the internal validation with the responsible clinicians prior to submission. These individuals also have to quality assure the registries for MINAP and BCIS across another very large hospital within the Trust.

The NHSE Standards Specification for Adult Congenital Heart Disease state (NHSE May 2016, B33L1) that a dedicated 1.0WTE data collection manager should be responsible for ACHD audit and database submissions in accordance with necessary timescales.

The numbers of patients treated for congenital heart disease at SBH Trust has increased by almost 25% since 2019. It appears that the identified data quality and support for NCHDA has not increased

correspondingly. This is due mainly to the extensive demands of the other larger registries on the CNS and Analyst that are currently tasked to look after the congenital cardiac data as well.

At SBH there is a specially created web-based Dendrite Intellect data collection system for NCHDA data. Data are mostly collected in real time at the point of treatment but it appears that some clinicians are better than others at entering the full dataset items.

Consent for External Validation of Notes.

Since May 2018, the General Data Protection Regulation has required that patients are made aware of how their data are collected and used. As such, NCHDA now no longer requires a specific consent to examine hospital case notes. If a patient has expressed a wish not to allow their case notes to be examined by others not connected to their care, these wishes will be respected.

A random list of case notes; 20 Samples and 10 Reserves were provided approximately 4 weeks prior to the Validation Visit. On the day all sets of case notes from the Sample were made available. These 20 patients had 22 procedures (10 operations and 12 catheter procedures).

Actions Undertaken Following Previous Validation Visit in 2024:

1. No actions reported

Data Quality Indicator

The DQI for the Trust for this visit (previous years in parentheses) is calculated to be **97%** (99, 98.25, 98) with domain scores Demographics 1.0 (.99, 1.0, 1.0), Pre Procedure .92 (.97, .95, .94), Procedure .97 (.98, .98, .96) and Outcome .99 (1.0, 1.0, 1.0)

This represents a good score although a little lower than last year. Well done. There were 919 variables reviewed for the 20 patients who underwent 10 operations and 12 catheter procedures. 38 discrepancies were identified.

The fields where most discrepancies (25/38) are in the Pre Procedure Domain of the DQI and this includes (amongst others) the fields for:

Previous Procedures	5
ACHD Risk Fields	6
Pre-Procedure Ventricular Function	6
Comorbidities	5
Height and Weight	2

Since 2009, separate DQI scores are being calculated for both catheters and surgery. The DQI is calculated from the case note review only. A minimum number of 5 records are required in either group for this to be done.

Year of visit	Data year being validated	Surgery Procedures	Catheter Procedures
2016	15/16	91.75%	93.75%
2017	16/17	97.75%	96%
2018	17/18	100% (3 records only)	96.5%
2019	18/19	99%	95.75%
2020	19/20	99.25%	97.25%
2021	20/21	95.75%	97.75%
2022	21/22	98%	97.75%
2023	22/23	98.5%	98.25%
2024	23/24	98.5%	98.75%
2025	24/25	98%	96.5%

The NCHDA pre visit Questionnaire confirmed that there are good processes and procedures in place with 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.

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. The Trust use a system known as Oracle Health (previously known as Cerner Millenium) Angiograms for instance are not available on the single sign-in to electronic health records (EHR), and there are still some paper records kept such as observation charts outside of ITU areas, and clinic notes etc at point of care.

There are also still some paper bound activity log books for areas such as some operating rooms for instance and some cath labs. The NCHDA data are in different parts of the Millennium application and each requires a separate log on and unique password.

It is reported that for the complete NCHDA dataset data to be collected between 2 and 4 applications (each with unique user id and password control) may have to be accessed.

Introduction

As previously stated, prior to the validation visit, the Congenital NCHDA return from the cardiac department at St Bartholomew's Hospital (SBH) indicate that a total of 512 procedures (107 surgical, 405 catheter procedures, 0 others, and 3 deaths within 30 days of a specific procedure) were undertaken during the data collection year April 2024 to March 2025.

The accuracy of the NCHDA data return was checked against each set of notes. The accuracy was then recorded on a database to enable the Data Quality Indicator (DQI) to be scored.

Review of notes at Barts Health NHS Trust

On the day 20 sets of case notes from the Sample list supplied were available in a digital format and displayed on a large screen for the Reviewers to see. Both the CNS and Data Analyst had created digital slides of various pages of the electronic health record (EHR). There was also access available to the Oracle Health EHR but on occasions this was a little slow and clunky to change pages and on at least 3 instances the connection was lost and took time to be reestablished. SBH are very 'paper-lite' with a mixture of electronic 'e' noting systems and with some retention of paper bound files.

1. As previously, the NHS Number was found on the hospital notes seen at this visit.
2. As noted at previous validations, there does not appear to be consistent documentation in one place for the data items such as NYHA, diabetes, pulmonary or ischaemic heart disease in every set of the hospital notes. These fields are part of the NCHDA dataset.
3. As reported in previous years, documentation of systemic and sub pulmonary ventricular function was variable and sometimes very difficult to identify and was often completely absent in the pre procedure hospital notes of patients who undergo catheter closure of a PFO.
4. For patients who have single ventricles it is only necessary to complete the field for the systemic ventricular function.
5. As previously described, there does not appear to be consistent documentation of time of skin puncture to time of sheath removal (as opposed to time/time out of cath lab) in catheter procedures descriptions. although it was reported at the 2021-25 visits that this data point is recorded in the cathlab information system Labyrinth. Labyrinth was made available during the validation.
6. The labels of implanted devices were fairly easy to find in the digital data presented from the EHR.
7. It was noted that the heights and weights of patients sometimes appears to fluctuate quite notably during a single short admission.
8. Regular reverse validation of data submitted to NCHDA is promoted as good practice and is an excellent way to gauge and sense check quickly and easily if data are correct, accurate and

complete. It is important that this exercise is undertaken with the responsible consultants on a regular basis to encourage clinician ownership of the data.

Case Ascertainment validation

Both sets of electronic data (activity logs) supplied for the activity ascertainment are described below.

Review of the Theatre log books

There are reported to be 10 cardiac operating theatres at SBH. The local Senior CNS and Data Manager offered the Reviewers extracts from the electronic log books of activity as recorded on the local iWeb applications.

As previously reported, it was difficult to scrutinise entries for younger patients whose procedures were not performed by known congenital cardiac surgeons as the diagnoses does not appear to be routinely recorded on each entry. However, for some entries a diagnosis of 'congenital insufficiency' was entered and this is rather ambiguous and not helpful when trying to discern if the procedure should be submitted to NCHDA. The Senior CNS for Cardiac Surgery Audit which includes NCHDA at this centre, also checks the cardiac surgery lists daily for the known congenital surgeons planned activity.

- 21 surgical records were identified that may be suitable for inclusion in NCHDA

Review of the Cath Lab Activity logs

There are reported to be 10 cardiac catheter labs at SBH. As above and at previous validation visits, the local CNS and Data Manager offered the Reviewers extracts from the log books of activity as recorded on the local iWeb application. It was difficult sometimes to identify exactly what procedure had been performed on the date stated and whether or not it was for congenital heart disease. Some patients appeared to have multiple entries but had been cancelled and not removed from the scheduler.

- 27 catheter records were identified that may be suitable for inclusion in NCHDA. Many of these were for electrophysiology procedures such as radio frequency ablation or device implant
- 2 submitted catheter procedures appear to be duplicates
- 1 submitted catheter procedure appears to have an error in it.

As previously reported, it was difficult to scrutinise entries for younger patients whose procedures were not performed by known congenital surgeons as the diagnoses does not appear to be routinely recorded on each entry.

Validation of Deceased Patients Diagnostic and Procedure Coding

Commencing with the validation of the 2013/14 data, the National Congenital Heart Disease Audit wish to verify the demographic, diagnostic and procedural data of deceased patients included in the year under review. The diagnosis and procedure coding will also be validated.

Three 30 day post procedural deaths were submitted in the data from SBH for the year 2024/2025. The Coroners Report or a detailed discharge summary were available for all 3 deaths and were extremely helpful for this part of the data Review. The Senior CNS for the NCHDA data confirmed that there are regular, at least quarterly, report enquiries run for life status of patients to enable timely record update of any out of hospital deaths.

1. 1 record appears to have an incomplete diagnosis.
2. All dates of death were correct
3. 2 death certificates (MCCD) were seen.

Completion of the field for Attribution of Death is required for NCHDA and this should be done by a clinician.

Case Note Audit 2024

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		11	9
2	NHS Number	19	19		11	8
3	Surname	20	20		11	9
4	First Name	20	20		11	9
5	Sex	20	20		11	9
6	DOB	20	20		11	9
7	Ethnicity	20	20	1 incorrect	11	9
8	Patient Status	20	20		11	9
9	Postcode	20	20		11	9
10	Pre Procedure Diagnosis	21	22	1 incorrect, 3 incomplete	11/12	10
11	Previous Procedures	47	52	1 incorrect, 4 absent	36/37	11/15
12	Patients Weight at Operation	21	22	1 incorrect	11/12	
13	Height	21	22	1 incorrect	11/12	10
14	Ante Natal Diagnosis	-	-		-	-
15	Pre Proc Seizures	22	22		12	10
16	Pre Proc NYHA	20	22	2 incorrect	10/12	10
17	Pre Proc Smoker	19	22	3 incorrect	9/12	10
18	Pre Proc Diabetes	22	22		12	10
19	Hx Pulmonary Dis	21	22	1 incorrect	10/12	10
20	Pre Proc IHD	22	22		9/12	10
21	Comorbidity Present	21	22	1 incorrect	11/12	10
22	Comorbid Conditions	31	36	2 incorrect, 3 absent	15/19	16/17
23	Pre Proc Systemic Ventricular EF	19	22	3 incorrect	10/12	9/10
24	Pre Proc Sub Pul Ventricular EF	19	22	3 incorrect	10/12	10
25	Pre-proc valve/septal defect/ vessel size	2	3	1 unable to validate	2/3	-
26	Consultant	22	22		12	10

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
27	Date of Procedure + Time Start	22	22		12	10
28	Proc Urgency	22	22		12	10
29	Unplanned Proc	-	-		-	-
30	Single Operator	4	5	1 incorrect	4/5	-
31	Operator 1	22	22		12	10
32	Operator 1 Grade	22	22		12	10
33	Operator 2	16	17	1 absent	6/7	10
34	Operator 2 Grade	16	17	1 absent	6/7	10
35	Procedure Type	22	22		12	10
36	Sternotomy Sequence	9	10		-	9/10
37	Operation Performed	22	22		12	10
38	Sizing balloon used for septal defect	4	4		4	-
39	No of stents or coils	-	-		-	-
40	Device Manufacturer	11	11		8	4
41	Device Model	11	11		8	4
42	Device Ser No	11	11		8	4
43	Device Size	8	8		5	3
44	Total Bypass Time	10	10		-	10
45	XClamp Time,	8	9	1 absent	-	8/9
46	Total Arrest	-	-		-	0
47	Cath Proc Time,	9	12	3 incorrect	9/12	-
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	7	8	1 incorrect	-	7/8
51	Post Procedure Seizures	22	22		12	10
52	Post Proc Complications	3	3		3	-
53	Date of Discharge	22	22		12	10
54	Date of Death	1	1		-	1
55	Attribution of Death	1	1		-	1
56	Status at Discharge	22	22		12	10
57	Discharge Destination	22	22		12	10

Data Quality Indicator Assessment:

The Overall Trust DQI = 97.0% Cardiology DQI = 96.5% Surgery DQI = 98.0%

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 .92**	
	Card .90	**Surg** .96
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 .97**	
	Card .96	**Surg** .98
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** .98

The Trust DQI = 97.0%

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

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DOMAINS	2022	2023	2024	2025
Demographics	1.0	1.0	.99	1.0
Pre Procedure	.94	.95	.97	.92
Procedure	.98	.98	.98	.97
Outcome	1.0	1.0	1.0	.99

Conclusions

On the whole the NCHDA data were accurate, well documented and of good quality. The NCHDA Senior CNS and audit nurse and analyst are to be commended for the considerable time spent in preparing many documents for this validation. Especially where they have other much larger cardiac audit responsibilities outside of ACHD. These individuals have no ring fenced time to maintain NCHDA and this is now of some concern.

The total number of ACHD procedures reported from SBH NHS Trust has increased by almost 25% since 2019. As noted above, the NHSE Standards Specification for Adult Congenital Heart Disease state (NHSE May 2016, B33L1) a dedicated 1.0WTE data collection manager should be responsible for ACHD audit and database submissions in accordance with necessary timescales.

The overall good DQI has been maintained in 2025 although has dipped by 2% this year to 97% since the last NCHDA Validation. There were 38 discrepancies in 919 variables. However, 25 variables appear to be discrepant in the Pre Procedure Domain of the Data Quality Indicator score.

The Validation Team were made aware that there is no regular reverse validation (where the submitted data are retrieved and reviewed) with the responsible clinicians where discrepant data could be corrected and validated. This is due to the CNS and Analyst for NCHDA having to coordinate and quality assure 2 other very large data collections. It appears that there could be more clinician ownership of the NCHDA data in order to ensure increased quality and accuracy.

As previously reported, there does not appear to be consistent documentation in a regular place in the EHR yet for data items such as NYHA, diabetes, pulmonary or ischaemic heart disease. These are part of the NCHDA dataset for ACHD patients.

Discharge dates were seen in all the patients daily narrative notes. There still does not appear to be consistently completed and itemised documentation of time of skin puncture to time of sheath removal in catheter procedures. As previously reported, xray dose and length of time of xray exposure are currently required fields for NCHDA and these were seen at this visit. Radiation exposure should be submitted in cGy CM^2 centigrays squared as required by the NCHDA.

Using the term ‘congenital insufficiency” to describe a cardiac diagnosis in activity log books is not helpful when, during a validation exercise, trying to discern whether or not a patient who has a procedure performed by a non congenital clinician actually fits the criteria to be included in NCHDA.

Validation of Deceased Patients Demographic, Diagnostic and Procedure Coding

A very small number of discrepancies in the coding were identified but all other data appeared to be correct.

Recommendations

1. I It is strongly recommended that in line with the ACHD Specialist Surgical Standards (NHSE May 2016, B33L1) that the Senior CNS Audit Nurse and Data Analyst for NCHDA have ring 1.0WTE fenced time, to be responsible for ACHD data quality monitoring with responsible clinicians as well as database submissions in accordance with necessary timescales
2. It is recommended that Standard Operating Protocols when finalised, are regularly reviewed for the Congenital data collection, to include detailed guidance on and **exactly who** is responsible (and in what timeframe) for;
    a. Ensuring that in line with the GDPR, all patients/parents and guardians are given full information of how their data are securely recorded, stored and where or who this information is shared with. And opt out explained to patients/carers.
    b. Ensuring responsible clinician input of the procedure data for each operation, diagnostic or catheter intervention at the point of the service delivery and ownership of the data;
    c. Encouraging clear succinct description of the exact diagnosis and procedure performed in the digital log books used. Using ambiguous terms such as 'congenital insufficiency' should always be avoided.
    d. Ensuring that radiation dose is recorded in cGY/CM^2
    e. Ensuring data fields that cannot be entered at the time of the procedure, such as extubation date and time and complications are completed as soon as possible and prior to discharge.
    f. 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
    g. Ensuring diagnosis coding reconciles with the procedure performed
    h. Recording of implanted device data and the placement of product labels in an agreed portion of the patients hospital record that can easily be validated.
    i. Leading the local review with the Lead Clinician for Congenital Heart Disease (and how frequently and in which forum for both disciplines)
    j. Where a patient has died within 30 days of a procedure, documenting whether or not there was a discussion with the coroner (when required), was discussed at an morbidity and mortality meeting and whether or not the death was related to the procedure as these are NCHDA dataset items.
    k. Identifying the responsible clinician for completing the field for Attribution of Death as this should not be a non clinical DBMs responsibility.
    l. Timely reverse validation together with the Clinical Lead for Congenital Cardiology and the responsible clinicians to encourage ownership of the data.

m. Reviewing/Updating the SOP at timely intervals

3. It is recommended that there is a more robust method of identifying patients with congenital heart disease who undergo pacing or EP procedures with adult cardiologists are clearly identifiable in the ePR activity logs to enable more accurate and timely data capture. The same applies for surgical patients who have their procedures with operators not normally associated with congenital cardiac surgery.
4. It is recommended that the Congenital dataset fields should be set to mandatory in any of the data collection software used.
5. It is recommended that where possible one of the NCHDA data team attend congenital MDTs to enable timely identification of patients who may come forward for interventions and operations and EP procedures. This forum may also support on going clinical education for the NCHDA team.
6. Documentation (either hard copy or on screen help) should be available to all staff in all areas where data are recorded real time.
7. Reporting of catheter closure of PFO is no longer required for NCHDA and these procedures should be submitted to the PFOC database supported by NICOR.