The National Congenital Heart Disease Audit

Procedures for
CONGENITAL HEART DISEASE

Data Quality Audit for April 2024 – March 2025
University Hospitals Birmingham NHS Foundation Trust

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Summary

Prior to this validation visit the combined Congenital NICOR data return from the Queen Elizabeth Medical Centre (QEB, UHB FT) when exported from the NCHDA database, indicated that some 324 (surgery 85, catheter 239, others 0, Deaths 5 within 30 days of a therapeutic procedure) procedures had been undertaken during the data collection year of 2024/2025.

Following review of the catheter laboratory and operating room activity logbooks on the day of the validation visit, 25 additional procedures were identified that may be suitable for this data collection. QEB will submit these cases where appropriate after internal validation.

This validation visit has been fully funded by UHB NHS Foundation Trust. The external assisting clinician was Dr H Elhadi a ST6 Specialty Trainee, with the NCHDA Clinical Nurse Specialist and Clinical Audit Nurse on site. A further NCHDA data manager attended the visit as an observer.

At the time of this visit the Data Manager at QEB had been in post for approximately 18 months. The post had been unfilled for the previous 18 months and the data collection and submission was entirely dependent on one consultant clinician investing may unpaid hours.

As reported since 2007, it is noted from the NCHDA Pre Visit Questionnaire that there does not appear to be any audit of data collection routines or activities, such as checking completeness or quality, or any Standard Operating Protocols for these processes. There does not appear to be any internal targets for completion of, and timeliness of, data collection and submission. It also appears that there is no regular reverse validation of the data once submitted to the NCHDA database.

20 sets of case notes are randomly selected from the submission from QEB.

This is the 21st successive external validation visit to QEB. The data for therapeutic interventional cardiology and congenital surgical procedures are input directly to the NCHDA web application (Qreg5) at QEB using a secure login. As previously reported, the Queen Elizabeth Hospital Birmingham (UHB/QEB) are a designated NHS England NHS Global Digital Exemplar. In August 2017 the electronic patient record system Oceano was launched. This is an internally developed and fully unified electronic medical record system that is used throughout this NHS Foundation Trust and known as the clinical portal.

Of the 5 consultant cardiologists for adults with congenital heart disease at UHB, 2 undertake interventional procedures.

There is very clear guidance on standards for data management in both paediatric and adult congenital surgical centres. Each Specialist ACHD Surgical Centre must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales. (B33 L1 NHSE July 2015). QEB was peer reviewed against these standards in June 2019.

The NCHDA recommendations on Agenda for Change Banding of this role is contained in the NCHDA Annual Report published in 2016. (Ref; p25, Section III, Congenital Cardiac Audit Teams, point 1).

Actions taken in response to the Recommendations at the 2024 Validation Visit:

1. QEB report that they are in the process of setting up a system of internal validation utilising the Dendrite Intellect system.

Consent for External Validation of Notes.

Since May 2018, the General Data Protection Regulation required that patients are made aware of how their data 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 or patient data to be examined by others not connected to their care, these wishes will be respected.

Data Quality Indicator

The provisional DQI for QEB is; **98%** (97.75, 97, 97). The Domain scores are; Demographics .99 (1.0, 1.0, 1.0,), Pre Procedure .96 (.98, .985, .95), Procedure .99 (.99, .98, .98), Outcome .98 (.94,.93, .92.

This is another very good score and an increase of 0.25%.

This DQI is based on the Random case notes sample of 20 patients who underwent 21 procedures (13 interventional catheters and 8 operations) that had been submitted during the year April – March 2024/25.

877 variables were reviewed, and 18 discrepancies were identified. The fields with the most errors were;

Comorbidities	4 discrepancies
Smoking status	4 discrepancies
Name and Grade of Operator 2	4 discrepancies

Differential DQI for Surgery and Catheters

As well as the overall DQI for each centre, DQI scores for surgery and catheters are being calculated. The scores are;

	Data Year Reviewed	Surgery	Catheters
2016	2015/16	66.75%	89.75%
2017	2016/17	89.75%	95.5%
2018	2017/18	94.5%	79.5% (4 records)
2019	2018/19	87%	89.25%
2020	2019/20	94.5%	95.3%
2021	2020/21	98.7%	96.75%
2022	2021/22	92.25%	98.25%
2023	2022/23	97%	99%
2024	2023/24	97%	97.75%
2025	2024/25	98%	98.5%

There are no identified accountable persons/people for NCHDA data collection or for quality and information validity. Data Submissions were not always timely or met deadlines during the 2024/5 data collection year.

Data Maturity in 2025

This Trust does not have a single unified digital health record system allows the user to see all of the patient data in one system. The users need several IDs and passwords to access certain parts of the Oceanic Clinical Portal databases.

There is still some reliance of paper records, particularly catheter lab activity log books.

Between 4-5 different databases need to be accessed to collect the NCHDA dataset for each patient and it is reported that this Trust has no plans to change anything in the short to medium term and is continuing to use paper bound ledgers to record activity in the catheter laboratories.

Introduction
Queen Elizabeth Medical Centre (UHB NHS FT) indicated that some 324 (surgery 85, catheter 239, others 0, Deaths 5 within 30 days of a therapeutic procedure) procedures had been undertaken during the data collection year of 2024/2025.

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

Review of the case notes at UHB
This centre has moved to an almost completely electronic patient record (ePR) and information was displayed directly from the ePR onto a large screen. The transition from screen to screen was very quick and easy to follow. Key data was easy to pick out.

1. As previously noted, a few patients whose date of birth was after 1988 had their field for ante natal diagnosis listed as unknown but on further investigation on the day it appears that these patients had procedures as children in Birmingham and this information may be available in the Children's Hospital notes.
2. Echo reports to assess ventricular function were available in the patients ePR and easily laid out and to follow.
3. Reports of cath lab procedures and fluoroscopy used, appeared to record radiation in milligray (mGY) on occasions rather than centigray (cGy). Centigray is the measurement required by NCHDA.
4. As previously noted, the ACHD DBM does not appear to have access to RIS to cross validate the radiation exposure time and dose if required. It would be helpful if this was available to the DBM.

Review of the Cath Lab Log Books at UHB
These are large double A3 size printed and bound ledgers that are used in each cath lab to record every procedure. The bound ledgers for cath labs 1-4 were presented.

There is no electronic log of catheter laboratory activity at this centre and no future plans to create a digital log book were reported to the Reviewers.

1. 17 catheter records were identified that may be suitable for inclusion in NCHDA. 6 of these are for post transplant ventricular biopsies.

2. 1 submitted catheter record appears to have a discrepancy

Review of the Operating Theatre Log Books at UHB

There are some 15 operating rooms at UHB. 3 of these are cardiac operating theatres. Operating Rooms 6 + 7 + 9 are primarily used for ACHD procedures. The Reviewers are again extremely grateful to Viv Barnett, the Adult Cardiac Surgery Data Analyst who was able to provide a spreadsheet from iSoft Galaxy electronic information system of much of the congenital cardiac theatre activity.

If ICD 10 and OPCS 4.8 codes are activated in iSoft Galaxy, reports can be generated to identify many congenital cardiac procedures.

1. 8 surgical cases were identified that may be suitable for inclusion in NCHDA.
2. 5 submitted records appear to have discrepancies in them

Validation of Deceased Patients Diagnostic and Procedure Coding

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.

It is strongly recommended that if information regarding a date of death for a pre-existing congenital patient on the NCHDA database post discharge is, or becomes available this should be submitted to that individual's record in the NCHDA registry also. This information can be obtained on a regular reporting cycle that could be run by the local cardiac information team from the NHS Spine, for instance monthly or quarterly.

There were 5 deaths within 30 days of a Specific Procedure at QEB during 2024-25 data collection year.

The findings were:

- All dates of death were found to be correct
- Some death (MCCD) certificates were seen
- Some coroners reports were seen also
- 4 records may have discrepancies in the field for comorbidities

Pre visit Review Questionnaire

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;
There is no current validation and Quality Assurance programme in place for this dataset and there is no training in NCHDA Data Management given to clinical colleagues about these data.
Information Governance Training is provided by NHS annual statutory and mandatory training.
There is or are identified accountable person/people for NCHDA data quality and information validity.
Data Submissions are Timely and Accurate to NCHDA but there are no internal deadlines for completeness.

Casenote Audit

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		12	8
2	NHS Number	20	20		12	8
3	Surname	20	20		12	8
4	First Name	20	20		12	8
5	Sex	20	20		12	8
6	DOB	20	20		12	8
7	Ethnicity	19	20	1 incorrect	11/12	8
8	Patient Status	20	20		12	8
9	Postcode	20	20		12	8
10	Pre Procedure Diagnosis	21	21		13	8
11	Previous Procedures	34	34		26	8
12	Patients Weight at Operation	21	21		13	8
13	Height	21	21		13	8
14	Ante Natal Diagnosis	-	-	3 patients unknown	-	-
15	Pre Proc Seizures	21	21		13	8
16	Pre Proc NYHA	20	21	1 incorrect	12/13	8
17	Pre Proc Smoker	17	21	2 incorrect, 2 absent	10/13	7/8
18	Pre Proc Diabetes	21	21		13	8
19	Hx Pulmonary Dis	20	21	1 incorrect	13	7/8
20	Pre Proc IHD	21	21		13	8
21	Comorbidity Present	19	21	2 incorrect	13	6/8
22	Comorbid Conditions	33	38	4 incorrect, 1 absent	25/26	8/12
23	Pre Proc Systemic Ventricular EF	21	21		13	8
24	Pre Proc Sub Pul Ventricular EF	21	21		13	8
25	Pre-proc valve/septal defect/ vessel size	3	3		3	-
26	Consultant	21	21		13	8

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
27	Date of Procedure + Time Start	21	21		13	8
	Proc Urgency	20	21	1 incorrect	12/13	8
29	Unplanned Proc	-	-		-	-
30	Single Operator	9	9		8	1
31	Operator 1	21	21		13	8
32	Operator 1 Grade	21	21		13	8
33	Operator 2	12	12		6	7
34	Operator 2 Grade	12	12		6	7
35	Procedure Type	12	12		13	8
36	Sternotomy Sequence	8	8		-	8
37	Operation Performed	21	21		13	8
38	Sizing balloon used for septal defect	4	4		4	-
39	No of stents or coils	1	1		1	-
40	Device Manufacturer	14	14		10	4
41	Device Model	14	14		10	4
42	Device Ser No	14	14		10	4
43	Device Size	10	10		7	3
44	Total Bypass Time	7	7		-	7
45	XClamp Time,	7	7		-	7
46	Total Arrest	-	-		-	-
47	Cath Proc Time,	12	13	1 incorrect	12/13	-
48	Cath Fluro Time,	13	13		13	-
49	Cath Fluro Dose,	13	13		13	-

	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	21	21		13	8
52	Post Proc Complications	3	4	1 incorrect	0/1	3
54	Date of Discharge	21	21		13	8
55	Date of Death	-	-		-	-
56	Attribution of Death	-	-		-	-
57	Status at Discharge	21	21		13	8
58	Discharge Destination	21	21		13	8

Data Quality Indicator Assessment:

The Overall Trust DQI = 98% Cardiology DQI = 98.5% Surgery DQI = 98%

DOMAIN	DOMAIN Score	
Demographics Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status,	**Overall .99**	
	Card .99	**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 .96**	
	Card .98	**Surg** .93
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** .99	
	Card .99	**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** .98	
	Card .98	**Surg** .98

The DQI for UHB Foundation Trust congenital cardiology is based upon the domain scoring below. The methodology for this DQI is provided in the paper The NICOR Audit – An Introduction to the Process.

DOMAIN.	Score 2025	Score 2024	Score 2023	Score 2022
Demographics	.99	1.0	1.0	1.0
Pre Procedure	.96	.98	.985	.95
Procedure	.99	.99	.98	.98
Outcome	.98	.94	.93	.92

Conclusions

On the whole the submitted NCHDA data were accurate, well documented, good quality and were appropriately recorded in the Theatre and Cath Lab activity logs and books that were seen. The DQI is 98%. This is a very good score, increased 0.25% from 2024 and further demonstrates how critical the role of a clinical ACHD data manager is within congenital heart disease.

We would also like to commend the ACHD Data Manager, for sterling efforts in identifying, collecting and submitting the NHCDA data for 2024/25 year. It is reported that that is no regular reverse validation of the data and no established data quality audit programme running for this registry yet. It is hoped that now that there is dedicated DBM in post these activities will be developed into practice over the coming months.

As noted elsewhere, the NHSE ACHD Specialist Surgical Standards (NHSE May 2016) recommendations state (B33L1) that each Level 1 centre must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales. As documented in previous NCHDA Reports, the location of an experienced 1.0WTE NCHDA DBM to the same operational hub as the ACHD nurses will provide much greater support to the role and the wider ACHD practice at this Centre.

The Validation Team would also like to thank the Cardiac Operations Managers for their support and ensuring the site visit was well run and well organised.

Many of the NCHDA data fields are now included in the congenital cardiac NHS Commissioning for Quality and Innovation (CQINs) dashboard. Each congenital centres' Data Quality Indicator Score (DQI) is also included in the quarterly dashboard.

Validation of Case Notes of Deceased Patients.

There were 5 deaths within 30 days of a Specific Procedure at QEB during the 2024/25 data collection year. There were very few discrepancies identified as discussed above.

NHCDA has always strongly recommended that if information regarding a date of death for a pre-existing congenital patient on the NCHDA database post discharge is or becomes available this should be submitted to that individual's record in the NCHDA registry also. There does not appear to be any regular reporting to identify these deaths.

Recommendations

1. It is recommended that in order to retain staff in the DBM role for NCHDA, that the NCHDA recommendations on Agenda for Change Banding of this role that is contained in the NCHDA Annual Report published in 2016. (Ref; p25, Section III, Congenital Cardiac Audit Teams, point 1) is adhered to.

2. It is recommended that Standard Operating Protocols are devised for the congenital data collection, to include detailed guidance on and exactly **who is responsible** for;
   a) 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.
   b) Input of congenital patients NCHDA required dataset items and at which point of service delivery
   c) Encouraging every responsible clinician or allied 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.
   d) Ensuring the diagnosis reconciles with the procedure performed.
   e) Recording the knife to skin time for all surgical procedures where it can be validated (ie perfusion or anaesthetic record).
   f) Recording radiation exposure in centigrays (cGy) for catheter procedures
   g) 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
   h) Reverse validation of the data submitted to NCHDA by responsible clinicians in conjunction with the Data/Audit Managers at least monthly. This will assist in informing the quarterly NHSE Dashboard reports and this is an essential practice to ensure data accuracy and correct analysis by the Specific Procedures Algorithm and Activity Algorithms.
   i) Where a patient has died within 30 days of a procedure, documenting
      - whether or not there was a discussion with the Medical Examiner/Coroner,
      - and/or was discussed at an Mortality and Morbidity meeting and
      - whether or not the death was related to the procedure as these are NCHDA dataset items.
      - Identifying the responsible clinician for completing the field for Attribution of Death as this should not be a non clinical DBMs responsibility.
      - Completing this field in the NCHDA dataset as part of the Mortality and Morbidity meeting with the clinical team

j) Ensuring that dates of death are reported for any QEB patient who has previously had a record submitted to the NCHDA
k) Leading the local review (and how frequently and in which forum for both disciplines)
l) Making timely submissions (monthly is recommended where possible) and
m) Including details of manufacturer, model and serial numbers of all implantable devices the procedure record for each patient.
n) Reviewing/Updating the SOP at timely intervals

3. It is recommended that the DBM at QEB is given access to RIS to cross reference radiation dosages as required.
4. It is recommended that all Congenital Audit or Data Managers visit other congenital centres at least once annually to experience a validation from the external reviewers perspective, network with a colleague(s), trouble shoot and problem share.
5. Involve all clinically relevant staff in a review of audit data collection, review and quality initiatives
6. It is suggested that it may be helpful for the NCHDA data manager in this post to attend MDT meetings to gain knowledge on cardiac diagnoses and procedures and to receive quarterly life status reports on all ACHD patients to enable dates of death to be updated promptly.