Procedures for
CONGENITAL HEART DISEASE
For April – March 2024-2025

Data Quality Audit

Liverpool Heart and Chest Hospital NHS Foundation Trust

2 July 2025

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Summary and Overview

Prior to this Validation Visit, the data return from The Liverpool Heart and Chest Hospital (LHCH), indicated that 622 therapeutic cardiac procedures were performed in patients with congenital heart disease during the data collection year of 2024-25. These are broken down as follows: Surgery 105, Catheters 504, Others 13, Deaths within 30 days of a Specific Procedure 5/6.

Following partial review of the catheter laboratory and operating room activity log books on the day of the validation visit, 9 additional procedures were identified that may be suitable for submission.

As previously reported, since 2018 LHCH has been commissioned to provide services for ACHD patients at Level 1. A full inpatient surgery and catheter interventions service commenced in December 2018. This is the seventh visit to LHCH since being commissioned as a Level 1 provider for Adult Congenital Heart Disease. At the time of this validation there were 7 ACHD consultant cardiologists at LHCH. 4 visiting consultant congenital cardiac surgeons from Alder Hey Children's Hospital operate at LHCH and 3 visiting cardiac interventionists also visit from Alder Hey, supported by a structural interventional cardiologist based at LHCH whom is also trained in CHD intervention. There is one ACHD cardiologist whom is an electrophysiologist and device implanter supported by one electrophysiologist with an interest in ACHD EP.

For reasons of logistics and capacity, ACHD patients who require diagnostic cardiac catheterisation undergo these procedures by a consultant congenital cardiologist at the Royal Liverpool University Hospital which is adjacent LHCH.

This external validation visit is fully funded by Liverpool Heart and Chest Hospital NHS Foundation Trust.

Overview at LHCH

There is an extremely strong, well established and embedded clinical audit culture at this Centre. As previously reported, data entry is at the point of treatment by clinician and throughout the centre using the Trust ePR. The demographic data for congenital procedures are identified from the Trust Patient Administration System and a separate data collection is then undertaken to ensure all relevant congenital NCHDA data are captured. As previously documented, there is a clinician lead. Prior to the NCHDA Data Manager being able to validate the data and check the completeness, the clinical coders complete the ICD10 and OPCS coding.

Both the cardiology and surgery parts of the congenital data collection are managed by a 1.0WTE Data Manager who has been in post for 15 months at the time of this validation. This role has been held by 3 different people over 3 years. None of these individuals had or have any clinical background.

Pacing and EP data are submitted to CRM. However, any therapeutic pacing or EP procedures in patients with congenital heart disease are required to be submitted to NCHDA.

Actions Taken Since Last Validation Visit in 2024:

- The ACHD Data Manager/Analyst began monthly meetings with ACHD Lead and cardiologists and surgeons, and also attends the weekly MDT meetings to ensure cases are being captured

Consent for External Validation of Notes.

Since May 2018, the General Data Protection Regulation 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.

Data Quality Indicator (DQI)

The overall DQI for the Trust is calculated to be (with previous years in parentheses) is **96.5%** (90.5,98.5, 99.25). The individual Domain scores are as follows; Demographics 1.0 (1.0, .99, 1.0, 1.0), Pre Procedure .92 (.83, .98, .99, .96,) Procedure .95 (.85, .99, .99,), Outcome .99 (.93, .98, .99, 1.0,).

This is a 6% increase on 2024 and is an excellent achievement. There were 50 discrepancies in 1018 variables.

This DQI is based on the records of 20 patients who underwent 24 procedures (17 interventional catheters and 7operations).

The fields with the most discrepancies are:

Previous Procedures	10 discrepancies
ACHD Risk Fields for smoking, diabetes, NYHA etc	9 discrepancies
Implanted Device Details	8 discrepancies
Operator Grades	7 discrepancies

It was again noted that in the Sample cohort there were a number of younger ACHD patients with dates of birth in the later 1990's. A proportion of these appeared to have unknown antenatal diagnosis fields but may have had procedures as children. It would be helpful if the hospital where these early procedures were undertaken could be noted in the patients records to assist with completing this field accurately in the NCHDA registry. Data managers at other congenital centres are always happy to liaise and assist with this.

Individual DQI for Surgery and for 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.

Year of Visit	Data Reviewed	Surgery	Catheters
2012	2010-11	Insufficient Sample	94.75%
2013	2011-12	Insufficient Sample	91%
2014	2012-13	Insufficient Sample	97.5%
2019	2018-19	92.75%	94%
2020	2019-20	95%	94.25%
2021	2020-21	Insufficient Sample	98.75%
2022	2021-22	99.25%	99%
2023	2022-23	99.25%	99%
2024	2023-24	92.75%	92.25%
2025	2024-25	97.5%	95.5%

The body of this report is drawn from answers given on the Congenital NICOR pre visit Questionnaire and from discussions on the day of the visit.

Introduction

Prior to the validation visit, the Congenital NICOR return from Liverpool Heart and Chest Hospital indicated that 622 therapeutic cardiac procedures were performed in patients with congenital heart disease during the data collection year of 2024-25. These are broken down as follows: Surgery 105, Catheters 504, Others 13, Deaths within 30 days of a Specific Procedure 5/6.

20 sets of case notes were selected for review. A Reserve list of 10 cases was supplied also and on the day. No sets of case notes from this list were required.

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

The Congenital NCHDA Data Auditor and one external Consultant in Congenital Cardiology undertook the site audit at LHCH.

As documented previously, most data are input at the point of treatment to a digital ePR. This is used throughout the ACHD patient journey. The information describing diagnoses and procedure performed are than translated into coded data ICD10 and OPCS 4.10 and entered into hospital information systems by clinical coders. It is only then that NCHDA Data Manager is able to access the data and add the very specific descriptions of congenital cardiac diagnoses, comorbidities and procedures used in this specialty from the AEPC Short Code List v6.1. Once complete, the data are then submitted manually via the NICOR NCHDA data portal.

In 2012 LHCH moved from using paper based hospital notes to using electronically held data collection systems.

Review of notes at LHCH

The DBM had prepared an electronic file of documents for each patient in the Sample and Reserve groups. The Validation Team reviewed each of 20 patients' files of electronic patient records.

There were also 20 folders of copies of these documents from the ePR, 1 for each patient being reviewed. These were filled with sheets of the printed ePR.

It was again noted that in the Sample cohort there were a number of ACHD patients who appeared to have had procedures as children. As noted elsewhere in this report, it would be helpful if the hospital where these early procedures were undertaken could be noted in the patients records to assist with completing this field accurately in the NCHDA registry. Recording previous procedures also informs risk attached to current and future procedures. Data managers at other congenital centres are always happy to liaise and assist with this.

1. There appeared that there was still irregular noting of whether or not the younger ACHD patients had been antenatally diagnosed.
2. There was also some challenges with finding regular standard documentation or template of NYHA status in the patients hospital records along with the 4 other specific ACHD risk fields. A note of a patients occupation can often help with identifying NYHA class.
3. Documentation of ventricular function was not always consistently seen on ECHO reports and this is a requirement of the NCHDA dataset.
4. The size where appropriate, make, model and serial number of any hardware implanted (with the exception of pacing leads) should always be submitted to NCHDA.
5. Catheter closure of PFO should now submitted to the NICOR PFOC database as from April 2025.

Review of the Log Books at LHCH

There are 5 cardiac operating rooms and a hybrid room at LHCH. Log books of activity are now an all electronic (digital) dashboard. Due to the unusually large amount of time that was required to validate the case note data (5.5 hours) the review of the log books was limited in order to provide at least 30 – 60 minutes feedback and discussion with the colleagues at LHCH.

A spreadsheet had been prepared for this part of the validation but it did not include patient diagnoses. It is very important to this part of the validation to ensure that the diagnoses reconciles with the procedure performed. The Reviewers requested that a new spreadsheet be prepared that did include the diagnoses for the patients.

As previously noted and again in 2025 it is not always clear whether or not a procedure is for congenital heart disease. The diagnoses descriptions were often vague and imprecise and it is not clear if any coding structure is consistently used by the individuals completing this record. The label ‘congenital insufficiency’ is not helpful for accurate NCHDA coding. Any diagnosis coding used should reconcile with the procedure performed. As previously suggested, it would be helpful to incorporate and train the users to use the NCHDA codes and descriptions as these would increase accuracy and specificity and also to have a mandatory field to indicate if a patient has congenital heart disease or not.

Due to time constraints in the months of April and May 2024 only were validated

1. 93 surgery records were not validated
2. 2 records were identified from the activity log that may have been missed from the congenital submission.

Cardiac Catheter Lab Log Book Review

There are 6 cath labs (+ the hybrid room) at this Centre.   As previously reported, the activity of the cathlabs are now collected digitally in CareCube. This is essentially a scheduling tool rather than a log of actual activity. Diagnostic catheters are mostly done at the adjacent Royal Liverpool Trust. It was not possible to check these for case ascertainment as no log this activity was available.

A large bound ledger of congenital cath lab activity was presented to the Reviewers. This ledger is beautifully kept and apparently is for congenital procedures only. However, the entries are handwritten and this was sometimes difficult to decipher, and there was often no diagnosis supplied included in the patient entry.

The findings are;

1. At least 1 of the submitted catheter records that were validated in this part of the review appear to have errors in it.
2. 289 records were not validated, many of these but not all, were for diagnostic catheters

Validation of Deceased Patients Diagnostic and Procedure Coding

Commencing with the validation of the 2013/14 data in 2014, the National Congenital Heart Disease Audit 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. Under GDPR regulation there is now no requirement for consent to validate these hospital data.

6 deaths in patients who had had procedures submitted for the during the 2024/25 data collection year . 5 of these were noted to have died within 30 days of a Specific Procedure. These 5 records were examined.

Findings:

The electronic hospital notes were made available to the Reviewers.

1 deceased patient was identified as not having congenital heart disease and this record was discarded and should be deleted from the NCHDA data collection

- All dates of death were correct
- 1 record appears to have a discrepancy in the field for Comorbidities
- 1 record appears to have additional procedure coding from the Procedure Performed field
- 1 record has absent implanted device details
- 1 record appears to have incomplete post procedure complications field

It is always helpful for this part of the validation to include copies of the death certificate (MCCD) and discussion notes from Medical Examiner or Coroner.

Pre Visit Questionnaire Assessment

The NCHDA pre visit Questionnaire was completed and returned prior to this visit and the Validation Team are the answers given confirm that there are good processes and procedures in place in regard to:

Maintaining 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 mostly Timely and Accurate.

Digital Maturity in 2025

This NHS Trust has a single unified digital health record system allowing users to see all of a patient data in one system relevant to their role in health care at the NHS Trust. This Organisation first moved from paper records to electronic records in 2013. This includes vital observations, clinic visit notes as well as in patients medical notes on progress, procedures and treatment. AllScripts is the name of the electronic medical records system used.

All activity in the operating rooms (OR) are recorded in the digital surgery booking system but ACHD catheter lab activity is recorded on mixture of paper and electronic logs. The NCHDA dataset requires up to 6 different sections of the digital and 1 set of paper records to be accessed. The data items are then collected and input directly to the NCHDA database manually.

Case note Audit 2024/25 Data.

20 patients underwent 24 procedures (17 caths, 7 operations)

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		14	6
2	NHS Number	20	20		14	6
3	Surname	20	20		14	6
4	First Name	20	20		14	6
5	Sex	20	20		14	6
6	DOB	19	20		14	6
7	Ethnicity	20	20		14	6
8	Patient Status	20	20		14	6
9	Postcode	20	20		14	6
10	Pre Procedure Diagnosis	21	24	3 missing important elements	14/17	7
11	Previous Procedures	35	38	2 incorrect, 1 absent	19/22	16
12	Patients Weight at Operation	24	24		17	7
13	Height	24	24		17	7
14	Ante Natal Diagnosis	-	-		-	-
15	Pre Proc Seizures	24	24		17	7
16	Pre Proc NYHA	19	24	3 incorrect 2 absent	13/17	6/7
17	Pre Proc Smoker	24	24		17	7
18	Pre Proc Diabetes	22	24	2 absent	15/17	7
19	Hx Pulmonary Dis	21	24	2 absent, 1 incorrect	17	7
20	Pre Proc IHD	22	24	2 absent	15/17	7
21	Comorbidity Present	24	24		17	7
22	Comorbid Conditions	36	39	2 absent, 1 incorrect	31/33	6
23	Pre Proc Systemic Ventricular EF	19	24	31/33	12/17	7
24	Pre Proc Sub Pul Ventricular EF	19	24	31/33	12/17	7
25	Pre-proc valve/septal defect/ vessel size	6	6		6	-
26	Consultant	24	24		17	7

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
27	Date of Procedure + Time Start	24	24		17	7
28	Proc Urgency	24	24		17	7
29	Unplanned Proc	-	-		-	-
30	Single Operator	7	7		7	-
31	Operator 1	24	24		17	7
32	Operator 1 Grade	21	24	3 absent	15/17	6/7
33	Operator 2	17	17		10	7
34	Operator 2 Grade	13	17	4 absent	10	3/7
35	Procedure Type	24	24		17	7
36	Sternotomy Sequence	7	7		-	7
37	Operation Performed	21	24	3 incorrect	14/17	7
38	Sizing balloon used for septal defect	-	-		-	-
39	No of stents or coils	0	4	4 absent	0/4	-
40	Device Manufacturer	19	20	1 absent	13/14	6
41	Device Model	19	20	1 absent	14/14	6
42	Device Ser No	19	20	1 absent	13/14	6
43	Device Size	17	18	1 absent	13/14	6
44	Total Bypass Time	5	5		-	5
45	XClamp Time,	7	7		-	7
46	Total Arrest	0	0		-	0
47	Cath Proc Time,	17	17		17	-
48	Cath Fluro Time,	15	15		15	-
49	Cath Fluro Dose,	15	15		15	-

	Parameter	**Total Score**	**Total No**	**Comments**	**Scores for Cardiology & Surgery**	
					C	**S**
50	Duration of Post Op Intubation	7	7		-	7
51	Post Procedure Seizures	24	24		17	7
52	Post Proc Complications	5	6	1 unable to validate	0/1	6
53	Date of Discharge	24	24		17	7
54	Date of Death	-	-		-	-
55	Attribution of Death	-	-		-	-
56	Status at Discharge	24	24		17	7
57	Discharge Destination	24	24		17	7

Data Quality Indicator Assessment:

The Overall Trust DQI = 96.5% Cardiology DQI = 95.6% Surgery DQI = 97.5%

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.

DOMAIN	DOMAIN Score		
	Overall	Card	Surg
Demographics Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status,	**1.0**	1.0	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	**.92**	.90	.98
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,	.95	.94	.92
Outcome Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination. Post Procedure Complications.	.99	.985	1.0

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.

DOMAIN	2025	2024	2023	2022	2021
Demographics,	1.0	1.0	.99	1.0	1.0
Pre Procedure,	.92	.83	.98	.98	.96
Procedure	.95	.86	.99	.98	.99
Outcome	.99	.93	.98	1.0	1.0

Conclusions

On the whole the submitted NCHDA data were accurate, well documented, good quality but did not appear to be always appropriately recorded in the electronic Theatre and Congenital Cath lab activity logs that were seen. This is the seventh NCHDA visit to LHCH since being commissioned to provide Level 1 adult congenital cardiac services in July 2018.

The Validation Team are particularly grateful to the Data Manager for detailing some of the documents needed at this review and grouping them together in individual files for the Reviewers to see and for printing them. The Reviewers would also like to thank the clinicians and Clinical Nurse Specialists who visited them during the day.

The Data Manager (DM) at this visit has been in this role within ACHD for just over 15 months. As noted elsewhere, there had been 3 post holders in this role within the two years prior that. In addition there is a Clinical Effectiveness Manager who has been in post for just 2 years that also supports the NCHDA registry. Congenital heart disease is a complex and complicated sub specialty of cardiology and it will take some considerable time for those without any prior clinical knowledge of this subject to become advanced beginners https://nursology.net/nurse-theories/from-novice-to-expert/ with the confidence to identify and prioritise some of the more simple disease profiles that many ACHD patients present with and then be able code them using the specific AEPC codes that are crucial for this registry and analysis. At LHCH clinical support is plentifully available from specialist nurses (CNS's) to Consultants.

That the Data Quality Indicator Score has increased by 6% this year is testament to this. There were 50 discrepancies (less than half of the total in 2024) in 1018 variables. Well done.

As noted at previous visits, the NCHDA Data Manager does not have automatic access to enable contemporaneous NCHDA congenital coding checks for procedures performed but has to wait until the clinical coding has been done. There is very little inter relation between clinical coding (ICD10 and OPCS) and NCHDA

It also appears that many of the NCHDA data fields are not mandatory in the Trust ePR and if they were, together with the NCHDA coding; this would make the data collection for the Registry much easier. If alongside this there was an abstraction tool that could export all the relevant NCHDA fields into a file such as a .csv without the need for the DBM to wait for the EHR record to be released by the clinical coders, this could enable more immediate internal validation of the data for quality and completeness than manually having to input each data item to the NCHDA database.

As previously reported it was sometimes very difficult to find explicit documentation of the specific ACHD risk fields. These data are required for every NCHDA entry. It was also challenging at times to find detailed and documentation regarding the exact previous procedures that had been undertaken at other hospitals within a congenital paediatric service elsewhere.

The electronic activity log was quite challenging to read, and often lacked specific diagnosis information that could be reconciled with the procedure performed. Therefore it was difficult to discern whether or not a patient was undergoing a procedure for congenital heart disease. The labelling of procedures as ACHD appeared to be a very random and inconsistent or absent. The term ‘congenital insufficiency’ is meaningless unless accompanied by the correct NCHDA diagnosis and procedure coding. A large bound ledger of congenital cath lab activity was presented to the Reviewers. This ledger is beautifully kept and apparently is for congenital procedures only. However, the entries are handwritten and this was sometimes difficult to decipher, and there was often no diagnosis supplied included in the patient entry.

Deaths

5 deaths had been identified in the submitted data. However, 1 patient was subsequently discarded as when reviewed this was not a patient with congenital heart disease. All dates of death were correct, however a number of discrepancies were identified in the 4 remaining records.

Recommendations

1. (unchanged from 2024) Consider embedding the NCHDA Dataset v6.1 coding in Trust ePR access in the areas where ACHD patients are seen such as in Out Patients, wards, operating rooms and cath labs to enable real time data entry with correct coding and descriptions of diagnoses, comorbidities, previous procedures and the procedure performed and make all NCHDA data fields mandatory entry. This will enable improved quality and accuracy of the data collected for this often high risk complex cohort of patients.
2. Creating an abstraction tool to then export all the NCHDA data fields to a .csv file or similar will allow for timely internal data validation for quality and completeness prior to submission to NCHDA without the need for the DBM to wait for ICD10 and OPCS4.6 coding as these have not relevance to this Registry.

3. It is recommended that the local Standard Operating Protocols (SOPs) already devised for the congenital data collection, continue to be reviewed at regular intervals to ensure their fitness for the purpose they are required to address ie:
    a. That in line with the GDPR, all patients/parents and guardians are given full information of how their data are securely recorded, stored, where this information is shared and who with. And op out explained to patients/carers.
    b. Identifying who is responsible for the input of congenital patients NCHDA required dataset items and at each point of service delivery
    c. Encouraging responsible clinician input of the procedure data and coding for each operation, diagnostic catheter or catheter intervention at the point of the service delivery
    d. Recording the knife to skin time for all surgical procedures where it can be validated (ie perfusion or anaesthetic record).
    e. 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
    f. Recording implanted device details on the operation or intervention procedure note.
    g. Reverse validation of the data submitted to NCHDA by responsible clinicians in conjunction with the Data Managers at least monthly.
    h. Running the NCHDA Activity Algorithm regularly using the R Code algorithm. This will help inform the quarterly NHSE Dashboard reports.

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i. Ensuring that dates of death are reported for any LHCH patient who has previously had a record submitted to the NCHDA
j. Leading the local review (and how frequently and in which forum for both disciplines)
k. Making timely submissions where possible and
l. Recording date and time of any discussion with a medical examiner/coroner in the case of a patient death with in 30 days of a therapeutic procedure for congenital heart disease and considered completion of the Attribution of Death field.
m. Identifying the responsible clinician for completing the field for Attribution of Death as this should not be a non clinical DBMs responsibility. This field is often best completed at the Mortality and Morbidity meeting with all clinicians present.
n. Reviewing/Updating the SOP at timely intervals

3 Also as previously recommended, it is suggested that greater attention to detail is used when recording procedures performed on patients with congenital heart disease in the electronic operating theatre and cath lab activity logs. Training staff to use the terms in the NCHDA dataset would be helpful and embedding the dataset in the electronic log would be very beneficial. The use of the term ‘congenital insufficiency’ is not precise enough to confirm whether or not a patient has congenital heart disease as defined by the NCHDA ACHD algorithm. The use of this term should be avoided.

4 It would also be helpful to document the dates chronologically of previous congenital procedures a patient may have had as a paediatric patient and whether or not they were antenatally diagnosed.

5 If possible, adapt the electronic e noting to include a template for the specific ACHD risk fields for NYHA, Smoking, Pulmonary Disease, Ischaemic Heart Disease and Diabetes etc

6 It is suggested that consideration be given to the possibility of a congenital colleague attending the aortic valve MDTs to assist with identifying any ACHD patients and ensuring that the correct data are submitted to NCHDA

7 It is further suggested that the BHL NCHDA data manager continues to attend the ACHD MDT to assist with identifying patients who may have future surgery or catheter investigations or interventions in a timely manner. This will also contribute to the DBMs ongoing ACHD education.

8 In conjunction with the person responsible for training, it is suggested that regular Quality Assurance and Governance training should be available to the DBM. Visits to other centres who are involved in NCHDA data collection and submission are encouraged at least once, preferably twice annually.

9 Regular training updates should be provided for all staff who may be involved with data collection and input