The National Congenital Heart Disease Audit Database

Data Quality Audit for
CONGENITAL HEART DISEASE
Apr 2024 - Mar 2025

The Royal Victoria Hospital, Belfast

17 June 2025

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Summary

This congenital validation visit by NCHDA was funded by the Health and Social Care Trust for Northern Ireland (HSCNI). The fiscal year reviewed is April to March 2024-2025. The validation was performed by an external consultant congenital cardiologist on site at Belfast Health and Social Care Trust (RVB) together with the NCHDA Clinical Data Auditor.

Prior to the review of the hospital log books, the data return to NCHDA from the adult congenital cardiac department of the Royal Victoria Hospital, Belfast (RVB) indicated that some 252 adult congenital heart disease procedures (surgery 54, catheters 197, 1 other, 1 death) have been undertaken during the data collection year of April 2024 to March 2025.

Following review of the catheter laboratory and operating room activity log books on the day of the validation visit, 1 additional procedure was identified and if found suitable will be submitted to the Registry.

Children's heart surgery ceased at this Centre in December 2014. Surgery and services for adult congenital heart disease (ACHD) patients (aged over 18 years) continue. As reported in since 2015, it is likely in the medium term that paediatric cardiac surgery will be undertaken in London Birmingham and Dublin until the new children's hospital in Republic of Ireland (ROI) is fully commissioned in (approximately) 2026.

As previously reported, since 2015, the submission of the congenital data across adult and paediatric cardiac services in RVB has been managed by several individuals. In March 2018 this role had been trimmed to 0.2WTE (1 day per week) with the surgery and catheter data being collected on two different systems and being facilitated by 2 individuals. Both of these individuals are Clinical Nurse Specialist (CNSs) within other larger sub specialties, one for adult cardiothoracic surgery and the other for Pulmonary Hypertension. There is a further non clinical data analyst who supports both NCHDA and the cardiothoracic NACSA registry.

Electronic Health Record (EHR) - EPIC

Until 5 June 2024, the majority of the congenital cardiac data entry was to HeartSuite – a standalone cardiac information system. Since 6 June 2024 when EPIC was launched in all health boards in Northern Ireland, all data are collected at the point of service on this electronic health record. EPIC is a nationwide electronic health records system that connects all primary and secondary care providers and enables the full medical record to be seen at each clinical attendance. EPIC has its own patient app known as MyChart that allows patients to also see their health records. This is similar to the NHS App.

The unique identifier known as the Health + Care Number has been used since July 2004 and is now widely seen in Northern Ireland and should be included in NCHDA data submissions. This identifier is similar to the NHS Number in England and Wales.

Actions Implemented since the last Validation Visit in 2024:

- There are ongoing issues with the EPIC build for NCHDA data collection mainly with respect to data extraction. This is very slowly being resolved

Patient Consent for External Validation of Case 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 to be examined by others not connected to their care, these wishes will be respected as part of the GDPR Opt Out. Currently there does not appear to be one generic consent form used across the whole NHS Trust that covers all specialties that describes exactly how patients data are used either for research nationally or internationally, or national/ international clinical audit. This inevitably leads to retrospective consent gathering for some patients whose data is part of NCHDA registry in particular.

Data Quality Indicator Scores (DQI)

The overall DQI for the centre is calculated to be (with previous year's in parentheses) **99%** (99.4, 99, 98.75**)** ,with domain scores Demographics 1.0 (1.0, 1.0, .99), Pre Procedure .99 (.98, .96, .97), Procedure .985 (.997, 1.0, .99), and Outcome 1.0 (1.0, 1.0, 1.0).

This is based on 20 patients with adult congenital heart disease who underwent 20 procedures (6 operations and 14 catheters). There were 8 discrepancies and 2 data items that were unable to be validated found in 884 variables.

The fields causing the most errors are:

Comorbidities	2 discrepancies
Previous Procedures	1 discrepancy

Since 2009, a separate DQI calculation is being made for surgery and catheter procedures where there is a minimum of 5 records in either group at the case note validation. The scores for RVB are:

Year of Visit	Data Years reviewed	Surgery DQI	Catheters DQI
2016	15-16	98.25%	98.5%
2017	16-17	96.25%	94%
2018	17-18	93.5%	96%
2019	18-19	91.25%	99%
2020	19-20	97%	96.25%
2021	20-21	98%	98.5%
2022	21-22	100%	98.75%
2023	22-23	99.25%	98.75%
2024	23-24	98.5%	99.75%
2025	24-25	99.5%	99.25%

The NCHDA Previsit Questionnaire confirmed that there continued to be 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

Digital Maturity

As mentioned elsewhere this NHS Trust commissioned EPIC and this was launched in June 2024. EPIC is an all encompassing health care record from tertiary centre to a community settings information system. It is planned that all legacy data will be imported into EPIC but there does not appear to be a confirmed timeframe to complete this.

With EPIC, one single sign in (log in) is all that is required to access all role specific, relevant patient data. There are however still one or two paper records kept ie operating room log books, vital observations and immediate clinic visit notes. There are no plans to change this at the time of this validation visit. On the whole just 2 (two) applications need to be accessed to complete the NCHDA data collection.

Introduction

Prior to the log book review by the NCHDA audit team, the data returned to NCHDA indicated that the cardiac department of the Royal Victoria Hospital had undertaken some 252 adult congenital heart disease procedures (surgery 54, catheters 197, 1 other, 1 death) have been undertaken during the data collection year of April 2024 to March 2025.

The NCHDA Congenital Audit Nurse and an external post CCT Fellow in congenital cardiology undertook the site audit in person.

20 sets of Sample notes were requested and a Reserve list of 10 further records were also supplied; in case any of the first 20 were irretrievable. On the day, 1 set of case notes were required from the Reserve list. The accuracy of the NCHDA data return was then checked against each set of notes and then recorded on a database to enable the Data Quality Indicator (DQI) to be scored.

Review of hospital case notes

Screen shots for the hospital notes and electronic records from EPIC were neatly prepared in folders for each patient reviewed. All were very well prepared and clearly labelled. This was extremely helpful. Where further information was required from EPIC, this was made available to the reviewers on a laptop computer in the room.

1. The operation notes were detailed, and anaesthetic information seen
2. The perfusion record was seen in all sets of surgical notes.
3. For patients who had had procedures as children at RVB or elsewhere in the UK, these historic case notes are not yet included in EPIC. It was also reported at this visit, that sometimes there was difficulty in confirming this in a timely manner as some historic notes have been lost or their location unknown.
4. All relevant previous procedures should be included in the patient record submitted to NCHDA regardless of which country or city they have been performed.
5. It also became clear that not all clinicians are completing all of the data fields in EPIC causing the CNSs to try to back fill these items.

Review of the Cath Lab and Theatre activity log

Cath Lab

The CNSs received the Cardiac Worklist that is generated by EPIC for cardiology. The CNSs are then able to scrutinise this list for patients with congenital heart disease. It was reported at this visit that there are now 6 Caths Labs at RVB and 2 cath labs at the City Hospital where some congenital procedures may be performed by clinicians from RVB. RVB is a designated PPCI centre.

Printouts from each cath lab were provided. These were ordered by date for each cathlab. It was again very difficult at times to discern if a younger patient was having a procedure for congenital heart disease but within EPIC it is easy to link into the patients e-health record to include or exclude from this registry.

It should always be noted that generally for EP or pacing patients aged over 18 years to be included in NCHDA, these patients must have been known and followed up during the years 0-18 years by a paediatric cardiology service. However, from time to time there may be exceptions to this.

1. 0 submitted catheter record appears to have an error in it.

Theatre Log (Books)

1 bespoke bound and ruled log book that is a register of all 3 cardiac theatres activity is being retained at RVB and this was made available for review. This is generally a very well-kept and neat log of all activity, patients identity labels are used for each entry and there is a good standard of precise descriptions of procedures undertaken.

1. 1 submitted surgery record appears to have an error in it.
2. 1 submitted procedure were identified that may not be for congenital heart disease and if not, should be deleted from NCHDA

Validation of Deceased Patients Diagnostic and Procedure Coding in NCHDA

Validation of Deceased Patients Diagnostic and Procedure Coding in NCHDA
Commencing with the validation of the 2013/14 data, the National Congenital Heart Disease Audit wish to verify any dates of death of deceased patients included in the year under review. The demographics, diagnosis, comorbidity, preoperative weights and procedure coding are also validated.

Medical Examiner

Since early in 2024 the NHS in England and Wales required all acute NHS Trusts to set up an Office of Medical Examiner

These positions are staffed by a team of medical examiners, supported by medical examiners officers.
The role of these offices is to examine deaths to:

- agree the proposed cause of death and the overall accuracy of the medical certificate of cause of death (MCCD) with the doctor completing it
- discuss the cause of death with bereaved families and relatives and establish if they have questions or any concerns with care before death
- act as a medical advice resource for the local coroner
- identify cases for further review under local mortality arrangements and contribute to other clinical governance processes.

The Health Service in Northern Ireland at the time of this validation visit, has not set up the office of Medical Examiner.

RVB reported nil deaths in ACHD patients within 30 days of a therapeutic procedure during the 2024/25 data collection year.

Currently any congenital cardiac deaths are discussed at the Trust Mortality and Morbidity meetings and recorded as appropriate.

Casenote Audit

	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	20	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	20	20	1 unable to verify	14	6
11	Previous Procedures	33	34	1 absent	29	4/5
12	Patients Weight at Operation	20	20		14	6
13	Height	19	20	1 absent	13/14	6
14	Ante Natal Diagnosis	-	-		-	-
15	Pre Proc Seizures	20	20		14	6
16	Pre Proc NYHA	20	20		14	6
17	Pre Proc Smoker	20	20		14	6
18	Pre Proc Diabetes	20	20		14	6
19	Hx Pulmonary Dis	20	20		14	6
20	Pre Proc IHD	20	20		14	6
21	Comorbidity Present	20	20		14	6
22	Comorbid Conditions	40	42	1 incorrect, 1 absent	27/28	11/12
23	Pre Proc Systemic Ventricular EF	20	20		14	6
24	Pre Proc Sub Pul Ventricular EF	20	20		14	6
25	Pre-proc valve/septal defect/ vessel size	4	4		4	-
26	Consultant	20	20		14	6

	Parameter	**Total Score**	**Total No**	**Comments**	**Scores for Cardiology & Surgery**	
					C	**S**
27	Date of Procedure + Time Start	20	20		14	6
28	Proc Urgency	20	20		14	6
29	Unplanned Proc	-	-		-	-
30	Single Operator	2	2		2	-
31	Operator 1	20	20		14	6
32	Operator 1 Grade	19	20	1 absent	13/14	6
33	Operator 2	17	17		12	6
34	Operator 2 Grade	17	17		12	6
35	Procedure Type	20	20		14	6
36	Sternotomy Sequence	6	6		-	6
37	Operation Performed	19	20	1 incorrect, 1 unable to validate	13/14	6
38	Sizing balloon used for septal defect	-	-		-	-
39	No of stents or coils	1	1		1	-
40	Device Manufacturer	18	18		13	5
41	Device Model	17	18	1 incorrect	12/13	5
42	Device Ser No	18	18		13	5
43	Device Size	13	13		9	4
44	Total Bypass Time	6	6		-	6
45	XClamp Time,	6	6		-	6
46	Total Arrest	-	-		-	-
47	Cath Proc Time,	13	14	1 incorrect	13/14	-
48	Cath Fluro Time,	11	11		11	-
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	6	6		-	6
51	Post Procedure Seizures	20	20		14	6
52	Post Proc Complications	-	-		-	-
53	Date of Discharge	20	20		14	6
54	Date of Death	-	-		-	-
55	Attribution of Death	-	-		-	-
56	Status at Discharge	20	20		14	6
57	Discharge Destination	20	20		14	6

Data Quality Indicator Assessment:

The Overall Trust DQI = 99% Cardiology DQI = 99.25% Surgery DQI = 99.5%

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

DOMAIN	**DOMAIN Score**	
Demographics Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status,	**Overall 1.0**	
	Card 1.0	**Surg** 1.0
Pre Procedure Pre procedure Diagnosis, Selected Previous Procedures, Patient Weight at Operation, Consultant, Antenatal Diagnosis, Pre Procedure Seizures, Comorbid Conditions, **Height, Pre Procedure NYHA, Pre Procedure Smoker, Pre Procedure Diabetes, Previous Pulmonary Disease, Pre Procedure Ischaemic Heart Disease, Comorbidity Present, Pre Procedure Systemic Ventricular Ejection Fraction, Pre Procedure Sub Pulmonary Ejection Fraction, Pre Procedure valve/septal defect/vessel size,** Note, the scores for his domain are affected by the selected previous procedure and pre procedure diagnosis	**Overall .99**	
	Card .99	**Surg** .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,**	**Overall .985**	
	Card .98	**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

Data Quality Indicator Assessment **2024-2025 data**:

The Overall Trust DQI = 99% Cardiology DQI = 99.25% Surgery DQI = 99.5%

DOMAIN	**2025** **24-25** **data**	**2024** **23-24** **data**	**2023** **22-23** **data**	**2022** **21-22** **data**
Demographics	1.0	1.0	1.0	.99
Pre Procedure	.99	.98	.96	.97
Procedure	.985	.997	1.0	.99
Outcome	1.0	1.0	1.0	1.0

Conclusions

On the whole the NCHDA data was accurate, well documented, good quality and was appropriately recorded in the relevant health records and log books. The NCHDA Review Team would like to particularly thank the clinical audit nurses and analyst for meticulously preparing all the sets of case notes. This greatly enables the process of the case note examination.

The DQI of 99% is another very good score. Having well supported individuals with congenital cardiac knowledge and experience greatly enhances not only the quality of the data but the completeness and timeliness of submissions as well.

As previously reported, the data for ACHD catheter procedures and surgery were being collected within EPIC with separate individuals for surgery and catheters facilitating thi. Now that RVB are using EPIC as a total eHR it is essential that all the historic data are preserved and fully available when required. EPIC is an overarching data management system as described above that may be used for tertiary, primary and secondary medical care. In Northern Ireland it is not currently being used in primary care although GPs can access records on a read only basis.

The New Congenital Heart Disease Review (NHSE May 2016) recommendation B33(L1) is that each Specialist ACHD Surgical Centre must have a minimum of 1.0 WTE dedicated cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales.

As reported since 2020 at RVB, that although there are two individuals (both CNSs) looking after these data they are barely 0.5WTE in total, covering this important role and the funding of this role does not appear to be spread equitably across the 2 clinical Divisions at this Trust who provide cardiovascular care.

The 2 individuals providing 0.5WTE have other much larger dedicated 1.0WTE clinical roles and it appears that NCHDA data is still considered a minor add-on activity when it is a complex and very detailed dataset that demands a considerable concentration, specific knowledge of cardiology and in particular knowledge of congenital cardiology terms, processes and procedures as well as great attention to detail. Neither of the CNS/DBMs have access to a secure email address such as NHSmail and it is not known if this NHS Trust is compliant with the NHS Mail standard DCB 1596.

The numbers of ACHD procedures may rise in the next 3-5 years as the service develops further. Timely reverse validation is considered essential practice to continually monitor accuracy and completeness. It was reported at this visit the abstraction tool used in EPIC to create the file for submission to NCHDA was not provided in a timely manner causing a three week delay. The CNSs' attendance at MDT meetings may help with identifying any patients who are considered for interventions or operation and may be admitted in the future and therefore more timely identity on the cardiology workstream list that is generated by EPIC.

Validation of Deceased Case Notes

As documented above there was 1 deceased patient in this years cohort who had died. However this was outside 30 days of a procedure

It was confirmed that regular electronic data checks are made on life status for NCHDA patients.

Recommendations as in 2024

1. It is strongly recommended that as a priority, included in forward planning for the congenital cardiac module of Encompass that a method of either transferring historic data from HeartSuite to EPIC or keeping a permanently accessible archive once the new data collection system is fully commissioned.
2. It is strongly recommended that the NCHDA CNSs and any other interested professional associates regularly liaise with other congenital centres data managers and clinical colleagues to learn from their experiences with the transfer to and then using EPIC in the congenital heart disease arena. The Level 1 centres are Guys & St Thomas's NHS Foundation Trust (mixed paediatric/ACHD) and Great Ormond Street NHS Foundation Trust. A Level 2 NCHDA ACHD centre is Manchester Royal Infirmary.
3. It is recommended that the role of NCHDA data manager/CNS for this registry is specifically documented and defined as 1.0WTE and appropriately and equitably financially supported and remunerated by both care divisions within RVB that provide cardiovascular care to meet the NHSE Standards (2016) minimum recommendation B33(L1). NICOR is now commissioned to publish NCHDA data quarterly within 2 weeks of end of each quarter.
4. It is recommended that Standard Operating Protocols are reviewed regularly to ensure that they adequately and specifically support the congenital data collection, to include detailed guidance on 'how to' and exactly **who** is responsible for and in what timeframe for each of the following;

    a. Ensuring all NCHDA patients are made aware of how their data are protected, stored and used and GDPR option for 'opt out' explained
    b. Real time input of the data for each congenital diagnostic and therapeutic procedure at the point of the service delivery in the cath labs and operating rooms, particularly data which cannot be entered at the time of the procedure, such as intubation time and complications
    c. Validity and completeness checking, 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
    d. Ensuring that all clinicians are encouraged to be responsible for their own their data where they are undertaking procedures and be involved in the local validation process
    e. Leading the local review (and in which forum for both disciplines)

   f. Making timely submissions of fully validated data, NHSE requires data to be submitted within 2 weeks of a procedure where possible (monthly within 2 weeks of month end, submission is essential) where possible and
   g. Monthly reverse validation at RVB against an acknowledged ‘gold standard’ record of activity and procedures performed.
   h. Regular monitoring of Specific Procedures allocation and Activity Analysis with R code or manually.
   i. Reviewing/Updating the SOP at timely intervals
   j. Capturing data on any out of hospital deaths of congenital patients
   k. When post procedural deaths occur during an inpatient stay, documenting any date and outcome of conversations with the Medical Examiner or Coroner in the deceased hospital notes as these are NCHDA dataset requirements.
   l. Identifying the responsible clinician for completing the field for Attribution of Death as this should not be a non clinical DBMs responsibility.

5. It is recommended that the NCHDA CNS/DBMs and any members of the clinical audit team who assist with this data collection should regularly attend the MDT meetings. These meetings are an educational forum as well identifying future congenital cardiac patients and their possible procedures. If patients previous history data is recorded correctly in the EPIC worklist, it should make identifying patients with congenital heart disease clearer.
6. It is also recommended to consider if there was ACHD clinician representation at MDTs for other allied cardiac specialties such as aortic valve disease, to identify whether or not a patient meets the ACHD criteria to be included in the registry..
7. As part of the DBMs ongoing training and development, it is suggested that visits to other centres to view their procedures and practices is a valued and important exercise in maintaining good standards.
8. All congenital clinicians (ST6 to Consultant) should be encouraged to volunteer to assist with at least one NCHDA validation as RVB has been very underrepresented in recent years.
9. It is also recommended that both CNS/Data Managers have access to their own email address or similar that meets the NHS Mail Standard 1596 compliance to enable secure discussion of sensitive information on a secure collaboration platform for health and social care colleagues.
10. RVB should be aware that from April 2025 the Partial Risk Analysis in Surgery v4 (PRAiS 4) will be used to review all surgery cases up to age 18 years. This is essentially used in paediatric centres but there may now be overlap in ACHD centres where any 16-18 year old patients with congenital heart disease undergo surgical procedures.

11. To ensure the EPIC build can provide the correct tools for monthly submission of data to NCHDA.