The National Congenital Heart Disease Audit

Procedures for CONGENITAL HEART DISEASE

Data Quality Audit for April 2023 to March 2024

Birmingham Children's Hospital NHS Foundation Trust

23 July 2024

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Summary

Prior to this validation visit the Congenital NICOR data return extracted on 17 June 2024 from the Birmingham Children's Hospital NHS Foundation Trust (BCH) indicated that some 746 (surgery 384, catheter 334, others 28, [deaths 5 within 30 days of a Specific Procedure]) procedures had been undertaken during the data collection year of 2023/2024 on children with congenital heart disease. Following review of the catheter laboratory and operating room activity log books on the day of the validation visit, no additional procedures were identified.

20 sets of hospital case notes are randomly selected from the BCH submission (the Sample) with a further 10 randomly selected as reserves. 2 case notes were used from the reserve list to replace those unavailable in the sample. A combined total of 22 procedures were reviewed, 12 catheters and 10 operations.

The HeartSuite information system continues to be used at Birmingham Children's Hospital to collect and manage all congenital cardiac data. The Trust is currently commissioning EPIC, an over arching clinical medical and patient information system that can be used throughout all specialites within the organisation and community health service. The 'go live' date is provisionally anticipated to be May 2025 and will be a 'phased' introduction over several months. Paediatric Cardiology is expected to be in the 2nd phase, later in 2025. HeartSuite will continue to be used until that time. .

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

BCH Overview

There is an 1.0WTE overall Cardiac Information Manager (IM) at BCH. The current IM was appointed in November 2020. There are a further 2 1.0WTEs supporting the cardiac information collection.

Actions taken since the 2023 Validation Visit:

- Monthly meetings with Catheter and Surgical leads to check and validate the previous months data. This helps with the on-going checking of coding accuracy, completeness and inclusion of complications.

- Refresher training has taken place for cardiac interventionists and Registrars highlighting the key fields that are sometimes missed in order to try and eliminate any missing data.
- Post validation visit information is presented at the Cardiac Audit meeting, where any issues found are raised and discussed in the meeting (open forum).

Data Quality Indicator

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

There were 2 discrepancies in 774 data variables. This represents another excellent DQI score and confirms that there are strong checks and balances in place at BCH to ensure good quality validated data is collected and submitted to NCHDA.

Separate DQI for Surgery and Catheters

Since the 2009 cycle of visits commenced, as well as the overall DQI for each centre, the DQI for surgery and catheters is being calculated. It is recommended that a minimum number of 5 procedures in either group are required for the differential DQI calculation.

DQI	Data Year Reviewed	Surgery	Catheters
2014(ii)	2013-14	96.75%	97%
2015	2014-15	98.5%	98%
2016	2015-16	98.75%	96.75%
2017	2016-17	100%	99.5%
2018	2017-18	98.75%	99%
2019	2018-19	99.5%	98.5%
2020	2019-20	99%	99%
2021	2020-21	99.75%	99.5%
2022	2021-22	99.25%	99.5%
2023	2022-23	100%	99%
2024	2023-24	99.75%	99.75%

The NCHDA pre visit Questionnaire was completed and returned prior to the validation visit. This confirmed that there are good processes and procedures in place in regard to:

Data Security and Management

Validation and Quality Assurance

Training in Data Management

Information Governance Training

There is or are identified accountable person/people for NCHDA data quality and information validity

Data Submissions are Timely and Accurate.

Introduction

As stated above, the NCHDA data return, prior to checking the theatre and catheter lab log books, indicated that the combined cardiac departments of the Birmingham Children's Hospital have undertaken some 746 procedures had been undertaken during the data collection year of 2023/2024 on children with congenital heart disease.

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

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

Review of notes

1. The paper hospital notes had again been meticulously prepared by the Congenital Audit Team
2. The relevant clinical records were highlighted in the case notes and therefore very easy to find
3. The NHS number was always easily available on the individual patients labels.
4. As previously reported, consistent documentation of ventricular function still needs to be improved and the Reviewers had to search through the hospital notes on occasions to validate these data.
5. Pre-procedure vessel size also does not appear to be consistently recorded in any particular document
6. On a small number of occasions it was difficult to find a concise and succinct list of a patients comorbidities. Sometimes these were documented over several entries but not all together in a concise list.
7. For patients aged 16 at the time of their procedure, there are 5 additional fields to be completed and it might be helpful to have an additional document template for the hospital notes for these patients.

Review of Log Books for Operating Rooms and Cardiac Catheter

Paper log books have not been kept at BCH for over a decade and have been replaced by Operating Room Information System (ORMIS) in both the cath labs and operating theatres. A

spreadsheet of all cases ordered by date in the operating room and the cath labs for the period under review was provided on a screen for the visiting clinician to review.
The findings were:

1. 0 records were identified that may be suitable for inclusion in NCHDA
2. 14 records for loop recorder placements appear in the data submission. These are not countable NCHDA procedures and should be deleted
3. 3 records were identified that may have discrepancies in them.

Validation of Dates of Death and Procedure Coding of Deceased Patients

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

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

5 deceased patients were identified in the data return for 2023-24 who had died within 30 days of their therapeutic procedure. The PRAiS sensitive fields were reviewed for each of the patients and the findings were:

- All data were found to be correct
- It is also noted that the discharge documentation for deceased patients continues to improve and this year, these notes were extremely detailed and it was much easier to identify the most important points relating to the NCHDA data collection.
- It is reported that the NCHDA Clinical Leads at BCH review the data for all post procedural deaths with the IM.

Casenote Audit

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		11	9
2	NHS Number	20	20		11	9
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		11	9
8	Patient Status	20	20		11	9
9	Postcode	20	20		11	9
10	Pre Procedure Diagnosis	22	22		12	10
11	Previous Procedures	37	37		13	24
12	Patients Weight at Operation	22	22		12	10
13	Height	22	22		12	10
14	Ante Natal Diagnosis	3	3		1	2
15	Pre Proc Seizures	22	22		2	-
16	Pre Proc NYHA	2	2		2	-
17	Pre Proc Smoker	2	2		2	-
18	Pre Proc Diabetes	2	2		2	-
19	Hx Pulmonary Dis	2	2		2	-
20	Pre Proc IHD	2	2		2	-
21	Comorbidity Present	22	22		12	10

22	Comorbid Conditions	21	21		16	5
23	Pre Proc Systemic Ventricular EF	22	22		12	10
24	Pre Proc Sub Pul Ventricular EF	17	17		10	7
25	Pre-proc valve/septal defect/ vessel size	2	3	1 incorrect	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	3	3		3	0
31	Operator 1	22	22		12	10
32	Operator 1 Grade	22	22		12	10
33	Operator 2	19	19		9	10
34	Operator 2 Grade	19	19		9	10
35	Procedure Type	22	22		12	10
36	Sternotomy Sequence	10	10		-	10

37	Operation Performed	21	22	1 incorrect	12	9/10
38	Sizing balloon used for septal defect	0	0		-	-
39	No of stents or coils	2	2		2	-
40	Device Manufacturer	8	8		6	2
41	Device Model	8	8		6	2
42	Device Ser No	8	8		6	2
43	Device Size	8	8		6	2
44	Total Bypass Time	10	10		-	10
45	XClamp Time,	8	8		-	8
46	Total Arrest	1	1		-	1
47	Cath Proc Time,	12	12		12	-
48	Cath Fluro Time,	12	12		12	-
49	Cath Fluro Dose,	12	12		12	-

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
50	Duration of Post Op Intubation	7	7		-	7
51	Post Procedure Seizures	22	22		12	10
52	Post Proc Complications	2	2		1	1
53	Date of Discharge	22	22		12	10
54	Date of Death	-	-		-	-
55	Attribution of Death	-	-		-	-
56	Status at Discharge	22	22		12	10
57	Discharge Destination	22	22		12	10

Data Quality Indicator Assessment:

The Overall Trust DQI = 99.6% Cardiology DQI = 99.75% Surgery DQI = 99.75%

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.

<table>
<tr><th>DOMAIN</th><th colspan="2">DOMAIN Score</th></tr>
<tr><td rowspan="2"><u>Demographics</u>

Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status,</td><td colspan="2">Overall 1.0</td></tr>
<tr><td>Card
1.0</td><td>Surg
1.0</td></tr>
<tr><td rowspan="2"><u>Pre Procedure</u>

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</td><td colspan="2">Overall .99</td></tr>
<tr><td>Card
.99</td><td>Surg
1.0</td></tr>
<tr><td><u>Procedure</u></td><td colspan="2">Overall .996</td></tr>
</table>

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,**	**Card** 1.0	**Surg** .99
Outcome Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination. **Post Procedure Complications.**	**Overall** 1.0 **Card** 1.0	**Surg** 1.0

DOMAIN.	Score 2024	Score 2023	Score 2022	Score 2021
Demographic	1.0	1.0	1.0	1.0
Pre Procedure	.99	.985	.99	.98
Procedure	.996	.997	.99	1.0
Outcome	1.0	1.0	1.0	1.0

Conclusions

The NCHDA data were of very good quality. The Data Quality Indicator (DQI) has remained excellent at 99.6%. This also demonstrates that there are very robust processes in place to ensure good quality data standards are maintained.

As previously reported, it is very clear that BCH NHS Foundation Trust consider the matter of collecting good quality, accurate and validated information about patient procedural activity to be of the highest importance and this has become embedded within the culture in the Cardiac Department. There were just 2 discrepancies in 774 variables. The Validation Team would particularly like to recognise the level of conscientiousness displayed by the Cardiac Information Manager and colleagues in preparing the hospital notes and various printed sheets so meticulously. This is a very large task to perform.

It is reported that clinicians input much of the NCHDA data to HeartSuite in the first instance. However it is not always clear that all colleagues are always involved in reverse validating their own data. It was confirmed during the site visit that BCH that the new electronic patient record system has a projected 'go-live' date of May 2025.

Finding descriptions of ventricular function prior to procedures was greatly improved again this year. This has been quite challenging in previous years. There was at times a little difficulty in finding clear, consistent and concise listing of a patient comorbidities. This is required data for NCHDA.

As previously reported, the standard and accuracy of the information recorded in ORMIS for surgery appears to continue to improve since the 2014 visit, however it is still a little poor in places for the catheter procedures. It was a little difficult at times to clearly identify exactly what catheter procedure had actually been performed in some of the entries.

Within the review of the deceased patients data there were no queries raised. The discharge summaries for deceased patients were of excellent quality with details very clearly laid out and easy to follow.

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

Recommendations

1. It is recommended that Standard Operating Protocols (SOP) for the data collection, to include detailed guidance on and exactly who is responsible for each of the following be regularly reviewed to ensure they fit the correct purpose. IE;
    i. Ensuring each patient/parent/guardian is given appropriate information in relation to how their data are recorded, stored and who it is shared with in line with GDPR 2018.
    ii. Input of congenital patients NCHDA required dataset items and at which point of service delivery
    iii. Encouraging every responsible clinician or allied healthcare professional to input complete data for each operation, diagnostic or catheter intervention at the point of the service delivery from admission to discharge and to own their data.
    iv. Recording the knife to skin time for all surgical procedures where it can be validated (ie perfusion or anaesthetic record).
    v. 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
    vi. Reverse validation of the data submitted to NCHDA by responsible clinicians in conjunction with the Data/Audit Managers at least monthly.
    vii. Where possible, running the PRAiS (Partial Risk Analysis in Surgery) analysis tool monthly. This will inform the quarterly NHSE Dashboard reports.
    viii. Ensuring that dates of death are reported for any BCH patient who has previously had a record submitted to the NCHDA
    ix. Leading the local review (and how frequently and in which forum for both disciplines)
    x. Making timely submissions (monthly is recommended where possible) and quarterly within 2 weeks of each quarter end is now mandated by NHSE.
    xi. Include all details of manufacturer, model and serial numbers of all implantable devices in the procedure record for each patient.
    xii. Ensuring the date and time of discussions with either the local Medical Examiner or Coroner are clearly recorded in the hospital notes of deceased patients.

xiii. Identifying the responsible clinician for completing the field for Attribution of Death as this should not be a non clinical DBMs responsibility.

3. In liaison with the person responsible for staff training and development in the Trust, to continue regular training/updates not only for the NCHDA Data Managers, but for all staff in the Department who may be involved with data input and validation. This should include regular Quality Assurance and Governance training and visits to other centres who are involved in NCHDA data collection and submission.
4. As previously recommended, to consider developing a standard discharge summary style for use throughout the cardiac department. Such a document should logically list all NCHDA pertinent information to that in-patient episode and previous interventions or operations.
5. All trainees (ST6 and above) should be encouraged to volunteer to participate in a NCHDA site validation visit as an external colleague to gain insights to the importance of maintaining good standards in data collection and quality management.