



## **The National Congenital Heart Disease Audit**

### **Procedures for CONGENITAL HEART DISEASE**

**Data Quality Audit for April 2021 to March 2022**

**Birmingham Children's Hospital NHS Foundation Trust**

**26 July 2022**

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## **Summary**

Prior to this validation visit the Congenital NICOR data return from the Birmingham Children's Hospital NHS Foundation Trust (BCH) indicated that some 901 (surgery 391, catheter 462, others 48, [deaths 12 within 30 days of a Specific Procedure]) procedures had been undertaken during the data collection year of 2021/2022 on children with congenital heart disease.

20 sets of hospital case notes are randomly selected from the BCH submission (the Sample) with a further 10 randomly selected as reserves. Four 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.

This validation visit has been fully funded by the Birmingham Women's and Children's NHS Foundation NHS Trust. This visit was supported remotely by the NCHDA clinical audit nurse via a MS Teams video conference facility and on site in person by Dr S Elgamel Consultant Congenital Cardiologist from Liverpool.

## **BCH Overview**

There is an overall Cardiac Information Manager at BCH. The current Information Manager was appointed in November 2020. There has been a 1.0WTE audit facilitator post for congenital heart disease at BCH since October 2010. There is a further 1.0WTE post within the cardiac information department that provides support for a number of audits and registries as well as NCHDA. BCH also have a Research Nurse part time (just under 0.5WTE per week) who assists in this Audit.

## **Actions taken since the 2021 Validation Visit**

1. Refresher training has taken place for Cardiac Interventionists and Registrars, highlighting key fields that are sometimes missed in order to try and eliminate any absent data
2. Standard Operating Protocols have been updated to support timely collection of good quality accurate data.

3. It was also reported at this visit that this NHS Trust is considering commissioning an overarching clinical medical and patient information system that can be used throughout all specialties within the organisation.

### Data Quality Indicator

The DQI score for BCH is **99.5%** (99.5, 99, 99,) The domain scores are; Demographics 1.0 (1.0, 1.0, 1.0), Pre Procedure .99 (.98, .985, .97), Procedure .99 (1.0, 1.0, .997), and Outcome 1.0 (1.0, .97, 1.0,).

821 data variables were validated and six discrepancies identified.

This represents another excellent DQI score.

### 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 five procedures in either group are required for the differential DQI calculation.

DQI	Data Year Reviewed	Surgery	Catheters
<b>2013</b>	2011-12	95.75%	94.25%
<b>2014(i)</b>	2012-13	98%	98%
<b>2014(ii)</b>	2013-14	96.75%	97%
<b>2015</b>	2014-15	98.5%	98%
<b>2016</b>	2015-16	98.75%	96.75%
<b>2017</b>	2016-17	100%	99.5%
<b>2018</b>	2017-18	98.75%	99%
<b>2019</b>	2018-19	99.5%	98.5%
<b>2020</b>	2019-20	99%	99%
<b>2021</b>	2020-21	99.75%	99.5%
<b>2022</b>	2021-22	99.25%	99.5%

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**

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 901 (surgery 391, catheter 462, others 48, [deaths 12 within 30 days of a Specific Procedure]) procedures had been undertaken during the data collection year of 2021/2022 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 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. The date and time of extubation is now much more clearly documented in the daily notes. This is required data for NCHDA.
5. As previously reported, documentation of ventricular function was sometimes difficult to find and it was noted that a variety of adjectives were sometimes used to describe the findings instead of approximate percentage of performance.
6. It was not always easy to find the times recorded for cath in and cath out in procedures taking place in the catheter laboratory.

## **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. Zero records were identified that may be suitable for inclusion in NCHDA
2. Four submitted records may have the incorrect Procedure Type entry.

## **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 System. For non-NHS patients or patients from Scotland or N. Ireland, the Information Team liaise with those colleagues as required.

12 deceased patients were identified in the data return for 2021-22 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:

- Two records may have incomplete comorbidities

PICU discharge summaries for the deceased patients whose case notes were examined were helpful and in almost all notes the multidisciplinary team or joint consultants committee (MDT/JCC) discussion document was frequently seen also. It was sometimes quite challenging however, to find clear and easy to see documentation of the entry in the hospital notes when a death was discussed with the local Medical Examiner or Coroner and the outcome of that conversation.

### Casenote Audit

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		10	10
2	NHS Number	20	20		10	10
3	Surname	20	20		10	10
4	First Name	20	20		10	10
5	Sex	20	20		10	10
6	DOB	20	20		10	10
7	Ethnicity	20	20		10	10
8	Patient Status	20	20		10	10
9	Postcode	20	20		10	10
10	Pre Procedure Diagnosis	21	22	1 incorrect	12	
11	Previous Procedures	53	53		38	9/10
12	Patients Weight at Operation	22	22		12	14
13	Height	22	22		12	10
14	Ante Natal Diagnosis	2	2		1	10
15	Pre Proc Seizures	22	22		12	1
16	Pre Proc NYHA	1	1		1	10
17	Pre Proc Smoker	1	1		1	-
18	Pre Proc Diabetes	1	1		1	-
19	Hx Pulmonary Dis	1	1		1	-
20	Pre Proc IHD	1	1		1	-
21	Comorbidity Present	22	22		12	10
22	Comorbid Conditions	11	13	2 incorrect	6/7	5/6

23	Pre Proc Systemic Ventricular EF	22	22		12	10
24	Pre Proc Sub Pul Ventricular EF	21	21		12	9
25	Pre-proc valve/septal defect/ vessel size	6	6		6	-
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	-
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	-	-		-	-

39	No of stents or coils	1	1		1	-
40	Device Manufacturer	10	10		8	2
41	Device Model	10	10		8	2
42	Device Ser No	10	11	1 incorrect	10/1 1	2
43	Device Size	8	9	1 incorrect	8/9	-
44	Total Bypass Time	8	8		-	8
45	XClamp Time,	7	7		-	7
46	Total Arrest	2	2		-	2
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	22	22		-	8
51	Post Procedure Seizures	3	3		12	10
52	Post Proc Complications	22	22		1	2
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
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Data Quality Indicator Assessment:

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

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	
<b><u>Demographics</u></b>	<b>Overall 1.0</b>	
Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status	<b>Card</b> 1.0	<b>Surg</b> 1.0
<b><u>Pre Procedure</u></b>	<b>Overall .99</b>	
Pre procedure Diagnosis, Selected Previous Procedures, Patient Weight at Operation, Consultant, Antenatal Diagnosis, Pre Procedure Seizures, Comorbid Conditions  <b>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</b>	<b>Card</b> .99	<b>Surg</b> .98
Note, the scores for his domain are affected by the selected previous procedure and pre procedure diagnosis		
<b><u>Procedure</u></b>	<b>Overall .99</b>	

<p>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,</p> <p><b>Time Start, Procedure Urgency, Unplanned Procedure, Single Operator, Sizing Balloon Used, No of Stents/Coils, Device Mfr, Device Model, Device Ser No, Device Size,</b></p>	<p><b>Card</b></p> <p>.99</p>	<p><b>Surg</b></p> <p>.99</p>
<p><b><u>Outcome</u></b></p> <p>Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination.</p> <p><b>Post Procedure Complications.</b></p>	<p><b>Overall 1.0</b></p>	
	<p><b>Card</b></p> <p>1.0</p>	<p><b>Surg</b></p> <p>1.0</p>

DOMAIN.	Score 2022	Score 2021	Score 2020	Score 2019
<b><u>Demographic</u></b>	1.0	1.0	1.0	1.0
<b><u>Pre Procedure</u></b>	.99	.98	.985	.97
<b><u>Procedure</u></b>	.99	1.0	1.0	.997
<b><u>Outcome</u></b>	1.0	1.0	.97	1.0

## Conclusions

On the whole the NCHDA data were of very good quality. The Data Quality Indicator (DQI) has remained at 99.5% and this is another excellent score. This also further demonstrates that there are robust processes in place to ensure good quality data standards are maintained.

It is very clear that BCH NHS 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 six discrepancies in 821 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 colleagues are always involved in reverse validating their own data. It was reported during the site visit that BCH is currently exploring moving to a fully digital ePR and hopes to be more paper lite in 2023.

Finding descriptions of ventricular function prior to procedures was greatly improved this year. This has been reported as very challenging in previous years. The date and time of extubation is now much more clearly documented in the daily notes. 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 patient's data there were two queries raised.

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:
  - 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
  - xi. Including details of manufacturer, model and serial numbers of all implantable devices 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.
  
3. In liaison with the person responsible for staff training and development in the Trust, regular training should be provided 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.