NCHDA Report BRC 2022

National Congenital Heart Disease Audit Report

On

Data Quality for Procedures for CONGENITAL HEART DISEASE

For April 2021 – March 2022

At

University Bristol Hospitals NHS Foundation Trust

15 June 2022

performed by Lin Denne, and Mr C Austin

Summary

Prior to the Log Book Review, the combined data return to National Congenital Heart Disease Audit (NCHDA) from the Cardiac Directorate of Bristol Royal Children's Hospital (BRC) and Bristol Royal Infirmary (BRI) indicates that a total of 986 procedures (333 Surgery, 636 Catheters, 17 others, 11 deaths) for the year 2021/2022 were undertaken. These numbers include adult congenital procedures carried out at Bristol Heart Institute (BHI).

This validation visit has been funded by the University Hospitals Bristol NHS Foundation Trust. Bristol Royal Children's Hospital (BRC) is part of the UHBristol NHS Foundation Trust.

BRC have had a dedicated congenital cardiac information team since 2014. Real time data input by all clinicians is encouraged and is mostly undertaken.

Patient Consent for External Validation of Hospital Notes

Under the General Data Protection Regulation (GDPR) of May 2018, it is expected that patients will be made aware by all organisations who care for them and produce data relating to their medical conditions to be open and transparent about how their data is being kept, used and who it is being shared with and how it may be disposed of. As such, NCHDA now no longer require individual patient informed consent.

Data Quality Indicator (DQI)

The DQI for the Trust is calculated to be (with the previous year in parentheses) **99.75%** (99.5% 99.25, 99.5,) with domain scores Demographics 1.0 (1.0, 1.0, .98,) Pre Procedure .99 (.98, .99, 997) Procedure 1.0 (1.0, 1.0 .98) and Outcome 1.0 (1.0, .985,1.0).

There were two discrepancies in a total of 814 variables across 20 patients who underwent 21 therapeutic procedures (13 catheter interventions, 8 operations).

This demonstrates that there are good processes and procedures in place to collect and validate accurate data at BRC.

Separate DQI for Catheters and Surgery

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.

Year	Data Year Validated	Surgery DQI	Catheter DQI
2012	11/12	91%	96.25%
2013	12/13	87%	96.5%
2014	13/14	98.25%	93.25%
2015	14/15	95%	94%
2016	15/16	99.25%	98.25
2017	16/17	99.25%	98%
2018	17/18	99.25%	99%
2019	18/19	98.75%	99.8%
2020	19/20	100%	99%
2021	20/21	98.75%	100%
2022	21/22	100%	99.75%

The body of this report is drawn from answers given on the NCHDA pre visit questionnaire and from discussions on the day of the visit.

Actions or changes undertaken since 2021 Validation Visit:

1. The data collection Standard Operating Protocols (SOPs)s are in place for both the paediatric and ACHD services. They are regularly reviewed. The Cardiac Data Team made monthly uploads to NCHDA in 21-22.

2. Training sessions have continued to be provided for all new members of staff both at BRC and BHI. The HeartSuite training programme is custom made for each staff group and covers all the steps required to be taken by those staff groups in order to follow the data collection SOP. The Cardiac Data Manager is in charge of the training programme which is being reviewed and improved on an ad-hoc basis whenever there is a change is NCHDA dataset, change of software or a change in internal processes. Three out of four members of data team carry out training and regularly shadow each

other's training sessions. Whenever changes take place, existing staff are also offered refresher training sessions. Detailed step-by-step guidance documents and shorter bullet point reminders are handed out to all new and existing members of staff and displayed in clinical areas. This is an ongoing process. Since 2020 the majority of these training sessions were carried out remotely via MS Teams and this is now the primary route for these sessions.

3. The Data Manager attended a virtual NCHDA site validation as an observer during 2022.

There has been a small change in the Cardiac Data Team – total WTE = 2.2 (from 2.4WTE):

- Information Analyst & Clinical Data Manager band 6 (0.8WTE)
- Assistant Data Manager band 4 (1.0WTE)
- Cardiac Data Quality and Specialist Audit Nurse band 5 (0.4WTE).

This represents a drop of 0.02WTE due to maternity leave.

Introduction

Prior to the validation visit the combined NCHDA return from the cardiac department of Bristol Royal Hospital for Children and Bristol Royal Infirmary indicated that 986 procedures (333 Surgery, 636 Catheters, 17 others, 11 deaths) for the year 2021/2022 were undertaken. These numbers include adult congenital procedures carried out at Bristol Heart Institute (BHI).

20 Sample sets of case notes were selected for review on each day. A reserve list of 10 was also supplied by NCHDA in case any of the first 20 were irretrievable. On the day no records were required from the reserve list to replace those that were unavailable from the sample. The accuracy of the NCHDA data return was then checked against each set of notes on each day.

One external Consultant in Cardiac Surgery undertook the patient notes audit on site at Bristol Royal Children's Hospital. The NCHDA Data Auditor supported the visit remotely via a Webex connection. The DBM for Cardiac Services at BRC in collaboration with colleagues, completed the pre visit self-assessment questionnaire.

Review of the notes

BRC is still in the process of moving towards ‘paper light’ hospital record keeping. This involves having a paper copy of patient’s notes only during an in-patient admission or an outpatient appointment. On discharge or completion of the episode the patient’s notes are immediately scanned onto an electronic patient record system ‘Evolve’. The process of scanning all historical patient notes is now established in the paediatric cardiac service and usually there are no significant delays with notes being scanned. In the Bristol Heart Institute (BHI) there are delays related to the scanning of patient notes which sometimes results in delayed upload of certain records to NCHDA. The delays in scanning became worse during Covid-19 pandemic and have not fully returned to normal in 21-22.

The patient case notes seen on the day of the validation visit, on the whole, were mostly fairly tidy and made up of very few traditional paper bound documents with others printed from the electronic patient records systems (ePR). The pages that were required to be seen by the reviewers had been meticulously tabbed with sticky notes and this was very helpful. Where the hospital record was totally electronic the various pages required to be viewed for the audit had been printed out and arranged in neat bundles.

1. The Joint Clinical Conference (JCC) discussion sheets were seen in almost all of the case notes and these were very detailed.
2. Cardiac echo reports were also seen and found to be very detailed although it was noted that the copies of details of echoes that were performed in the referring centres outside of BRC were often absent.
3. As previously reported, the cardiac catheter procedure sheet was easy to locate and well laid out in the BRC hospital notes seen. Labels from implantable devices were often stuck to these sheets and this was useful for validation of these data.
4. As previously reported, the PICU discharge summaries were very detailed and therefore extremely helpful in validating the perioperative data fields.
5. In the discharge summaries of ACHD patients it was difficult at times to find the detail of the timeline of actions and interventions of an episode.
6. As previously reported, NYHA status did not appear to be routinely recorded in the hospital records of patients aged over 16 at admission clerking or outpatient

preadmission appointments. This field is part of specific pre procedure risk assessment used in the NCHDA ACHD dataset.

Validation of Deceased Patients Diagnostic and Procedure Coding

Commencing with the validation of the 2013/14 data, the National Congenital Heart Disease Audit will request to verify any dates of death of deceased patients included in the year under review. The diagnosis and procedure coding along with the Partial Risk Adjustment in Surgery (PRAiS) fields will also be validated. 11 deaths occurred within 30 days of a therapeutic catheter or surgical procedure and these case notes were examined in closer detail. One of these cases appeared to be for a patient who did not have congenital heart disease and this case should be deleted from the data submission. The PRAiS sensitive fields (demographics, diagnosis, previous procedures, comorbidities and procedure performed) were reviewed for each of the patients and the findings were:

- All dates of death were correct
- No discrepancies noted in any other field
- The death summaries for paediatric patients were very informative but for adult patients, it was sometimes difficult to find the same level of detail
- It was not always easy to find documentation or confirmation of whether or not there had been a discussion with the Medical Examiner or Coroner after a patient's death.

As reported in 2021, an annual query is also now run to compare life status on NHSE Summary Care Record with known NCHDA patients as a further check for patients who may have died post discharge.

Review of the Operating Theatre Log Books

Log books from BRC operating theatres and one Hybrid room were made available. BRI theatres 1, 2, 9 and Hybrid were offered for review. The log books that were reviewed are bound bespoke ledgers with large wide ruled lines for entries. Each entry is handwritten and at times this was difficult to decipher. Some entries used the patient identity labels which was helpful. The log book for operating room 3 (paediatric) was also offered for review.

1. Zero records were identified in the log books that may be suitable for submission to NCHDA.

Review of the Cath Lab Log Books at BRC/BRI

There is one paediatric catheter laboratory at BRC and five catheter laboratories at BRI. The log book for the paediatric catheter laboratory was made available. A printout from the CCW electronic information system was provided. This is considered to be the ‘gold standard’ of recording of activity in the adult congenital heart disease cath labs.

1. As previously reported, the CCW printout was fairly easy to use. It was not always clear whether or not the cases were for ACHD patients.
2. Zero submitted catheter records may have discrepancies in them
3. Zero record was identified that may be suitable for inclusion in the NCHDA data submission.

The Congenital NICOR 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.

Data Quality Indicator Assessment:

20 Patients who had 21 Procedures – 13 Caths and 8 operations.

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

22	Comorbid Conditions	28	28		16	12
23	Pre Proc Systemic Ventricular EF	19	21	2 unable to validate	11/13	8
24	Pre Proc Sub Pul Ventricular EF	19	21	2 unable to validate	11/13	8
25	Pre-proc valve/septal defect/ vessel size	8	8		8	-
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
28	Proc Urgency	21	21		13	8
29	Unplanned Proc	0	0		-	-
30	Single Operator	2	2		3	8
31	Operator 1	21	21		13	8
32	Operator 1 Grade	21	21		13	8
33	Operator 2	18	18		10	8
34	Operator 2 Grade	18	18		10	8
35	Procedure Type	21	21		13	8
36	Sternotomy Sequence	6	6		-	6
37	Operation Performed	21	21		13	8
38	Sizing balloon used for septal defect	5	5		5	-

39	No of stents or coils	1	1		1	-
40	Device Manufacturer	10	10		10	-
41	Device Model	10	10		10	-
42	Device Ser No	10	10		10	-
43	Device Size	9	9		9	-
44	Total Bypass Time	6	6		-	6
45	XClamp Time,	5	5		-	5
46	Total Arrest	0	0		-	0
47	Cath Proc Time,	13	13		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	7		-	7
51	Post Procedure Seizures	21	21		13	8
52	Post Proc Complications	4	4		3	1
53	Date of Discharge	21	21		13	8
54	Date of Death	-	-		-	-
55	Attribution of Death	-	-		-	-

56	Status at Discharge	21	21		13	8
57	Discharge Destination	21	21		13	8

The Overall Trust DQI = 99.75% Cardiology DQI = 99.75% Surgery DQI = 100%
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 1.0</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** 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

The Trust DQI = 99.75%

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

DOMAINS	2019 18/19	2020 19/20	2021 20/21	2022 21/22
Demographics	1.0	1.0	1.0	1.0
Pre Procedure	.98	.99	.98	.99
Procedure	.997	1.0	1.0	1.0
Outcome	1.0	.985	1.0	1.0

Conclusions

On the whole the NCHDA data are accurate, well documented, good quality and were appropriately recorded in the Theatre and Cath Lab logs books that were seen for BRC.

The Data Quality Indicator Score for this validation visit has remained excellent at 99%+ in what has been another extraordinarily challenging period due the pandemic situation. The DQI score is also now included in the NHSE CQINs quarterly dashboards for congenital heart disease.

The Trust has allowed a decrease the 0.2WTE in the congenital cardiac team information team. BRC are still recovering from the COVID 19 pandemic impacts on patient admissions and numbers of procedures and there has been little or no requirement for the many hours overtime that are normally required to ensure that all the NCHDA data are collected, validated and of good quality prior to submission. The reviewers conclude that this is indicative as the centre returns to full pre pandemic NCHDA activity levels and further demonstrates that the full complement of 3.0WTEs (2.0WTE for paediatric and 1.0WTE for ACHD) to manage these data are still required as specified in: Standard B32(L1) in NHSe Paediatric Congenital Heart Disease Standards – Specialist Children's Surgical Centres, 2016 and Standard B33 (L1) NHSE Congenital Heart Disease Standards for ACHD Surgical Centres 2016.

As previously reported while the reviewers note that there are three individuals in post covering 2.2WTEs to support all of congenital heart disease data collection, just one of these individuals (0.4WTE) has a clinical background.

The case note bundles were again meticulously prepared and this is of great assistance to the reviewers. This Trust are now paper-lite with almost any paper notes that may be generated being scanned to the digital record very quickly after patient discharge.

Review of Deceased Patients case notes.

As stated above, all data were found to be correct. The death summaries for paediatric patients were very informative but for adult patients, it was sometimes difficult to find the same level of detail. In some instances, the Coroner's Report was also included.

Recommendations

1. Active consideration of appointing a further 1.0WTE data manager for the NCHDA adult congenital (ACHD) data.
2. It is recommended that the Standard Operating Protocols (SOPs) for the congenital data collection, (paediatrics and ACHD), continue to be reviewed to ensure that they include detailed guidance on and **exactly who** is responsible (and in what timeframe) for:
   i. Input of the data for each procedure and at which point of the service delivery
   ii. 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
   iii. Leading the local review (and how frequently and in which forum for both disciplines)
   iv. Making timely submissions (monthly is recommended)
   v. Timely reverse validation with all relevant clinical teams
   vi. Monthly to quarterly PRAiS analysis as required
   vii. Ensuring that relevant case and procedural records and logs are extracted and printed from electronic sources (HeartSuite, ORMIS, CCW, MEDWAY etc) in advance to be easily accessible by the Auditors on the day of the visit.
   viii. Checking for any out of hospital deaths that may have occurred in the congenital cohort.
3. As recommended in 2011-21, it is suggested that consideration be given to identifying congenital procedures in the BRI electronic theatre log books as the entries are made. Precise, specific congenital diagnosis descriptions would be very helpful in this application.
4. It is recommended that care should be taken when handwriting entries of each procedure performed in any bound log books to ensure clarity and specificity.
5. Entries to the cath lab information system CCW should continue to be reviewed monthly and if necessary, staff given extra training to more specifically describe procedures performed and how to identify patients with adult congenital heart disease rather than inherited heart disease. Shortening of names of procedures should be avoided as this may lead to mis interpretation. The use of recognised clinical coding such as OPC, ICD10/11 and IPCC should be encouraged when it becomes available.

6. It is also recommended that the DBMs should visit with other centres that send congenital cardiac data to NCHDA.
7. It is recommended that regular, training sessions and updates for all staff who may be involved with data input and should continue to be part of the induction process for new staff. This should include adult congenital staff members, who may be working solely within the BRI.