National Congenital Heart Disease Audit Report

On

Data Quality For Procedures for CONGENITAL HEART DISEASE

For April 2020 – March 2021

At

University Bristol Hospitals NHS Foundation Trust

15 June 2021 2021

performed by Lin Denne, and Dr A Deri

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 898 procedures (342 Surgery, 544 Catheters, 12 others, 12 deaths) for the year 2020/2021 were undertaken. These numbers include adult congenital procedures carried out at Bristol Heart Institute (BHI). The total figure is approximately a 20% lower number of procedures than in 2019- 2020

This validation visit has been funded by the University Hospitals Bristol NHS Foundation Trust. Bristol Royal Children's Hospital 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) **99.5%** (99.25, 99.5, 99) with domain scores Demographics 1.0 (1.0, .98, 1.0) Pre Procedure .98 (.99, 997, 98,) Procedure 1.0 (1.0 .98, 99) and Outcome 1.0 (.985,1.0, 99).

There were 4 discrepancies in a total of 882 variables across 20 patients who underwent 24 therapeutic procedures (17 catheter interventions, 7 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 5 procedures in either group are required for the differential DQI calculation.

Year	Data Year Validated	Surgery DQI	Catheter DQI
2011(ii)	10/11	92%	98.25%
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%

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 2020 Validation Visit:

1. In BHI (where ACHD procedures are performed) 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 have become have longer during Covid-19 pandemic.
2. The planned move for the paediatric cardiac service to move over to CCW system (currently used in BHI) for generating procedure logs has been slowed down by technical difficulties, so the older SENSIS information system is currently used.
3. Changes were made to the process of generating discharge summaries in the paediatric cardiac service. Now both BHI and paediatric service use the in-house Medway EPR for this purpose. The majority of other documents in the paediatric service are currently generated either within the HeartSuite information system or with the help of the voice recognition system Big Hand.
4. There has been a change in BHI ACHD lead. Dr Gergely Szantho has taken this role.
5. The Data Manager attended a virtual NCHDA site validation as an observer during 2020.

<u>No Changes in the Cardiac Data Team – total WTE = 2.4</u>:

- Information Analyst & Clinical Data Manager band 6 (25.5 hours per week)
- Cardiac Data Manager band 5 (15 hpw)
- Assistant Data Manager band 4 (37.5 hpw)
- Cardiac Data Quality and Audit Nurse band 5 (11.5 hpw)

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 898 procedures (342 Surgery, 544 Catheters, 12 others, 12 deaths) for the year 2020/2021 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 Congenital Cardiology undertook the patient notes audit on site at Bristol Royal Childrens 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

The patient case notes on the whole were mostly fairly tidy made up of very few traditional paper bound documents with others printed from the ePR. Many of 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 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.
3. 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. The PICU discharge summaries were very detailed and therefore extremely helpful in validating the perioperative data fields.
5. As previously reported, 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 pre admission 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 Paediatric Risk Adjustment in Surgery (PRAiS) fields will also be validated. 12 deceased patients were identified in the data return for 2020-21. Of these, 8 deaths occurred within 30 days of a therapeutic catheter or surgical procedure and these case notes were examined in closer detail. The PRAiS sensitive fields 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

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 theatre 3 and one Hybrid room were made available. It was confirmed at this visit there are no plans to move to a totally electronic log book for the OR. 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. However as previously reported it was not always clear exactly what procedure had been performed due to the sometimes difficult to decipher handwritten noting.

1. 1 of the submitted records for congenital surgery may have a coding error
2. It appeared that sometimes the dates of procedures were incorrect in the log book but correct in the submitted data
3. 0 records were identified in the log books that may be suitable for submission to NCHDA
4. 6 submitted records were not validated in the log book check
5. It was difficult to identify ACHD patients who may have undergone therapeutic procedures as there does not appear to be a standard way to indicate these patients in the logs.

Review of Cath Log Books

There is 1 paediatric catheter laboratory at BRC and 5 catheter laboratories at BRI. The bound log book for the paediatric catheter laboratory was made available. A printout from the CCW electronic information system was provided for BRI. This has replaced Centricity CARDASS system that was used previously. This is considered to be the 'gold standard' of recording of activity in the adult congenital heart disease cath labs. A printout was provided for the date range April 2019 – March 2020. CCW is much more detailed than the previous information system and there is the opportunity to use ICD10, and OPCS coding as well as the specific congenital cardiac coding that that is used by NCHDA

1. The CCW printout was fairly easy to use except where the names of procedures had been shortened.
2. It was not always clear whether or not the cases were for ACHD patients or not.
3. 3 submitted catheter records may have discrepancies in them
4. 0 record was identified that may be suitable for inclusion in the NCHDA data submission
5. 2 submitted records were not identified in the activity log check.

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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

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		15	5
2	NHS Number	20	20		15	5
3	Surname	20	20		15	5
4	First Name	20	20		15	5
5	Sex	20	20		15	5
6	DOB	20	20		15	5
7	Ethnicity	20	20		15	5
8	Patient Status	20	20		15	5
9	Postcode	20	20		15	5
10	Pre Procedure Diagnosis	24	24		17	7
11	Previous Procedures	33	33		18	15
12	Patients Weight at Operation	24	24		17	7
13	Height	23	23		17	4
14	Ante Natal Diagnosis	3	4	1 incorrect	-	¾
15	Pre Proc Seizures	24	24		17	7
16	Pre Proc NYHA	7	7		6	1
17	Pre Proc Smoker	7	7		6	1
18	Pre Proc Diabetes	7	7		6	1
19	Hx Pulmonary Dis	7	7		6	1
20	Pre Proc IHD	7	7		6	1
21	Comorbidity Present	23	24	1 incorrect	17	6/7
22	Comorbid Conditions	17	19	2 incorrect	11	6/8
23	Pre Proc Systemic Ventricular EF	24	24		17	7
24	Pre Proc Sub Pul Ventricular EF	23	23		16	7
25	Pre-proc valve/septal defect/ vessel size	8	8		8	-
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	3	3		1	2
30	Single Operator	3	3		3	-
31	Operator 1	24	24		17	7
32	Operator 1 Grade	24	24		17	7
33	Operator 2	21	21		14	7
34	Operator 2 Grade	21	21		14	7
35	Procedure Type	24	24		17	7
36	Sternotomy Sequence	7	7		-	7
37	Operation Performed	24	24		17	7
38	Sizing balloon used for septal defect	2	2		2	-
39	No of stents or coils	4	4		4	-
40	Device Manufacturer	13	13		11	2
41	Device Model	13	13		11	2
42	Device Ser No	13	13		11	2
43	Device Size	9	9		8	1
44	Total Bypass Time	5	5		-	5
45	XClamp Time,	4	4		-	4
46	Total Arrest	1	1		-	1
47	Cath Proc Time,	17	17		17	-
48	Cath Fluro Time,	17	17		17	-
49	Cath Fluro Dose,	17	17		17	-

	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	12	12		1	11
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

The Overall Trust DQI = 99.5% Cardiology DQI = 100% Surgery DQI = 98.75%

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 .98</td></tr>
<tr><td>Card
1.0</td><td>Surg
.95</td></tr>
<tr><td rowspan="2"><u>Procedure</u>

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,</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>Outcome</u>

Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination.
Post Procedure Complications.</td><td colspan="2">Overall 1.0</td></tr>
<tr><td>Card
1.0</td><td>Surg
1.0</td></tr>
</table>

Data Quality Indicator Assessment

The Trust DQI = 99.5%

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	2018 17/18	2019 18/19	2020 19/20	2021 20/21
Demographics	1.0	1.0	1.0	1.0
Pre Procedure	.98	.98	.99	.98
Procedure	.997	.997	1.0	1.0
Outcome	.99	1.0	.985	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.

It should be noted that it appears that there has been an approximate 20% drop in overall congenital procedures for April – March 2020 – 2021 at BRC primarily caused by the SARS-COV-19 pandemic. With this decrease the 2.4WTE congenital cardiac team report that there has been little or no requirement for the many hours overtime that are normally required to ensure that all the data are collected, validated and of good quality prior to submission. The Reviewers conclude that this is indicative and demonstrates that the full complement of 3.0WTEs (2.0WTE for paediatric and 1.0WTE for ACHD) to manage these data are required as indicated in: Standard B32(L1) in NHSe Paediatric Congenital Heart Disease Standards – Specialist Childrens 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 4 individuals in post covering 2.2WTEs to support all of congenital heart disease data collection, just one of these individuals (0.2WTE) 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 Coroners Report was also included.

Recommendations

1. Active consideration of appointing a further 0.5WTE 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) and
   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 2011-20, 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 hand writing entries of each procedure performed in any bound log books to ensure clarity and specificity.
5. Entries to the cath lab information system CCW at BRI 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 be part of the induction process for new staff. This should include adult congenital staff members, who may be working solely within the BRI.

NCHDA Report BRC 2021