The National Congenital Heart Disease Audit Combined Reports on Procedures for

CONGENITAL HEART DISEASE

Data Quality Audit For the year
1 April 2024 to 31 March 2025

For the combined

Evelina London Children's Hospital, Guys and St Thomas's, Royal Brompton and Harefield NHS Foundation Trust

1st + 2nd September 2025

performed by Lin Denne, and Dr A Tarmahomed

Summary and Background Overview

The Guys and St Thomas' NHS Foundation Trust (GUY) merged cardiovascular services with the adjacent Royal Brompton NHS Foundation Trust (NHB) in February 2021. This is the third NCHDA validation of the combined data submission of the new NHS Trust. All National Congenital Heart Disease (NCHDA) data from the now fully unified Trusts have been submitted under the GUY identifier since 1 April 2022.

The new Organisation migrated to EPIC health care record system on 4 October 2023. All legacy systems such as HeartSuite or Labyrinth ceased to be used from that date. All legacy data has been imported into EPIC. EPIC is an all encompassing health care record from tertiary centre to a community settings information system. All the NCHDA data are submitted via EPIC. This is the first full year's data review since EPIC became the e health record at this Trust.

The combined Congenital NICOR data return, prior to this validation visit, from the combined NHS Foundation Trusts indicated that a total of 1964 cases had been undertaken during the year 2024/25.

This number of procedures are broken down further below.

Year	Total	Surgery	Catheters	Others
2021/22 GUY	787	331	441	15
2021/22 NHB	1096	348	742	6
2022-23	1888	696	1175	17
2023-24	1984	692	1275	17
2024-25	1964	701	1237	26

This validation visit to GUY has been fully funded by the combined NHS Foundation Trust. Day 1 of this visit took place was undertaken virtually using MS Teams. Day 2 of the visit was face to face with the external clinician, the NCHDA Clinical Audit Nurse, and external consultant cardiac surgeon and 1 other NCHDA Data Manager from another centre on MS Teams.

The procedures being validated at this visit are for patients with congenital heart disease that take place at Royal Brompton, Harefield, London Evelina, Guys' and St Thomas' Hospitals.

The Validation Team are pleased to note that prior to site visit, the local NCHDA Data audit team had performed a further internal data review and identified one patient that had been omitted from the data submission.

For Day 1 of the Validation

The lead clinical audit nurse and NCHDA data team at GUY were all either remotely interacting using MS Teams and facilitating parts of this validation or were on site. All team members continue to have equal remote access to required data systems and data bases. Both the NCHDA Clinical Audit Nurse and the external clinicians were on site on Day 2 of the visit. The external clinician colleague was Dr A Tarmahomed, Specialty Trainee in Paediatric Cardiology from Birmingham and observing was Mr Joe George, cardiac surgeon also from Birmingham.

Until October 2023, the congenital cardiac department at GUY and NHB had been using many different information systems in all clinical areas. GUY and NHB, were separate NHS Trusts and became unified in 2022 into one Organisation, had been compiling digital data that inter located for the previous 20+ years of NCHDA site visits.

As noted above, the combined Trust implemented the new electronic healthcare registry (eHR) system in all areas across all sites as part of the EPIC roll out in October 2023.

The NCHDA Data team at GUY at the time of this visit comprises of 2.0 WTEs Clinical Nurse Specialists in Congenital Cardiac Audit and Research Data Management (CNSs) and a 2.0WTE data analysts. The team works collaboratively to meet the needs of the now combined Department. At the time of this validation visit there was a 1.0WTE analyst post that was vacant and not yet re recruited.

Data are input to EPIC by clinical colleagues. Each user has a specific job role identity in EPIC that provides the level and range of access related to their position.

The GUY Centre have a well-established embedded culture in clinical audit and all colleagues are encouraged to own their data. Almost all data are collected contemporaneously and reviewed within a prescribed timeframe by the data team. Discrepancies are immediately referred back to the responsible colleague(s) for urgent review and amendment.

The Congenital Data Team at the combined Organisation receive every patient booking to a cardiothoracic operating room or cath lab within the cardiac domain across the whole of the Trust into a worklist generated by EPIC. Each entry is reviewed by the congenital data team and any procedures that are not for patients with confirmed congenital heart disease are voided from the work list. The data, once completed and validated locally, are submitted electronically to the NCHDA database managed by NICOR.

Actions Taken since the previously separate Validation Visits to GUY and to NHB in 2024:

- The NCHDA Data teams in GUY and NHB have been formally aligned into one
- The NCHDA dataset is updated for current version
- There is now a more timely review / submission of data.

Consent for External Validation of 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 previously reported, across the Guys and St Thomas' and Royal Brompton NHS Trust hospital sites, there are now displayed and available in all places of patient activity, a leaflet that describes how the Organisation use and share patients personal information to deliver and improve healthcare. There is information in the leaflet that describes what information is kept, how safe it is and whom it may be shared with and whether it is anonymised or not. There is also information for patients who may wish to object to their data being shared and how to do this. The document also contains information on patients' rights to access their medical data.

The overall Data Quality Indicator (DQI) for the combined data and separate DQI for Surgery and for Catheters at GUY

The DQI for the Trust is calculated to be (with the previous visit scores are in parentheses), is **94.5%** for the 24/25 data (97.75%, 98.5% at the previous 2 validations).

There were 61 discrepancies in 1048 variables. The individual fields where the main discrepancies are seen are:

Operator 1 + 2 Names and Grades	10 discrepancies
Device manufacturer, serial number and size	8 discrepancies
Comorbidities	8 discrepancies

In the Procedure Domain that covers the fields for operators names and grades, procedure performed, device manufacturer, model and serial number amongst others; part of the DQI there were over 20 discrepancies noted.

DQI for Surgery and for Catheters

As at the previous visits, a separate DQI is being calculated for both surgery and catheters where there are at least 5 surgical and 5 cardiology case notes in the randomised sample.

Year of visit	Data Year Validated	Surgery	Catheters
2022 GUY	21/22	100%	99.25%
2022 NHB	21/22	92.5%	95.75%
2023	22/23	98.5%	98.5%
2024	23/24	97.75%	97.0%
2025	24/25	94.75%	93.5%

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.

Introduction

The NCHDA data return, extracted prior to this validation visit, from the combined Congenital Cardiac Department of Guy's and St Thomas' NHS Foundation Trust (GUY) indicated that a total of 1964 cases had been undertaken during the year 2024/5. As stated elsewhere, 20 cases were randomly selected for the case note review.

20 sets of notes (the Sample) were requested and a Reserve list of 10 other cases was supplied approximately one month prior to this validation visit. On the day of the visit, 1 set of notes were required from the Reserve list.

The Reviewers scrutinised the pages of the Trust EPIC eHR for each patient to validate each data item as required on a large screen.

The accuracy of the NCHDA data return was then checked against each set of patients eHR notes to enable the Data Quality Indicator score (DQI) to be calculated.

Review of the digital patient notes on the shared screen at GUY.

All GUY hosts were very responsive to requests from the Reviewers to check other pages or tabs of the digital eHR documentation when requested. Where print was small and difficult to read, this was magnified for the Reviewers to see.

1. As at the previous validation visits, individual patient data were meticulously organised and this aided the review greatly.
2. For 1 ADHD patient who had 2 procedures, there was variance on whether or not the patient was a smoker or ex smoker at the date of each procedure.
3. The comorbidities fields for 6 records were incomplete.
4. The pre procedural measurement of vessels and defects should be as outlined in the NCHDA Data Manual
5. The Operator 1 and 2 names should always be entered in NCHDA in exactly the way the procedure was undertaken, ie Operator 1 being the primary colleague and the assisting colleague as Operator 2.
6. Details of implanted devices are required to be placed in the specific field for this data please and not combined with the product serial number.
7. The NCHDA Data Manual explains which data is required for the registry and this should always be followed to maintain consistency.

Review of the Operating Theatre and Cath Lab Activity Logs at Guys and St Thomas's

This is the first full year (April 24 – March25) that the Trust has been using EPIC.

As described elsewhere, the congenital CNS's and Data Analysts receive all booked cardiology and cardiac surgery episodes on one WorkList generated by EPIC and shared between them whenever a patient is allocated to a cath lab or operating room. The congenital cardiac clinical audit team then investigate each patient on the list and void (remove) the cases that are not for patients with congenital heart disease. The remaining procedures are then systematically followed up in the patients electronic hospital record (eHR) that is part of EPIC to ensure all data are collected in a timely manner by all relevant clinician colleagues.

Following validation of the Excel spreadsheet that contained the combined legacy systems and WorkList data for congenital catheter and surgery procedures the findings were:

- 2 surgery procedures were identified that may have been missed from the data submission.
- 5 submitted records for surgery may have errors in them
- 1 submitted record for surgery may have a duplicate entry
- 1 submitted surgery record may need to be removed if not for congenital heart disease
- 4 catheter procedures were identified that may have been missed from the data submission
- 2 submitted catheter records was identified that may have an errors in them
- 2 submitted catheter records may have duplicate entries
- 1 submitted catheter record may need to be removed if not for congenital heart disease

Validation of Deceased Patients Diagnostic and Procedure Coding GUY

Since 2013 all case notes for patients who have died following a procedure for congenital heart disease have their case notes examined and validated against the PRAiS sensitive data fields.

At the time of the data extraction for this site visit there appeared to be 12/38 deaths within 30 days of a Specific Procedure

Of the data relating to the deceased patients reviewed the findings are;-

- 2 records may have discrepancies in the comorbidities field
- 1 record appeared to have some absent complications
- All other data were confirmed as correct
- Some MCCD were seen
- Some very good discharge notes were seen but others were a little sparse in details of the course of events prior to death.

The NCHDA clinical audit team at the Organisation confirmed that regular life status checks are run Trustwide against NHS Spine and EPIC is automatically updated from this when a death has occurred.

Pre Visit Questionnaire Completion

The Congenital NICOR pre visit Questionnaire was completed and returned prior to the validation visit from the combined NHB and GUY. This confirmed that there are established 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 Maturity in 2025

As documented elsewhere, GUY now use EPIC and as such all users have access via their unique user ID and password to all relevant parts according to their role in health care at the Trust. The electronic health record is an overarching patient information system and encapsulates all hospital and community care.

All cardiac admissions to GUY are automatically logged on a worklist and then each is screened by the NCHDA data team to identify those patients with a congenital cardiac diagnosis. Each time a patient receives treatment or has a consultation is recorded in the worklist.

There are no paper records used.

All activity in the operating rooms and catheter labs are recorded in EPIC at the point of service. There are no bound log books. The NCHDA data fields are completed automatically on a Smartform within EPIC and are internally validated prior to submission to the national database.

Just 1 login is required to access, complete, quality control and validate all of the NCHDA dataset for each congenital patient prior to submission to the national database.

Casenote Audit GUY

Case note audit based on 20 patients who underwent 11 operations and 16 catheter procedures

	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	19	20		10	10
8	Patient Status	20	20		10	10
9	Postcode	20	20		10	10
10	Pre Procedure Diagnosis	27	27	1 absent element, 2 incorrect elements	14/16	10/11
11	Previous Procedures	46	46		40	6
12	Patients Weight at Operation	24	27	3 incorrect	14/16	10/11
13	Height	26	26		16	10
14	Ante Natal Diagnosis	3	3		-	3
15	Pre Proc Seizures	27	27		16	11
16	Pre Proc NYHA	10	10		8	2
17	Pre Proc Smoker	9	10	1 incorrect	7/8	2
18	Pre Proc Diabetes	10	10		8	2
19	Hx Pulmonary Dis	10	10		8	2
20	Pre Proc IHD	10	10		8	2
21	Comorbidity Present	26	27	1 incorrect	15/16	11
22	Comorbid Conditions	49	57	4 incorrect, 4 absent	25/30	24/27
23	Pre Proc Systemic Ventricular EF	27	27		16	11
24	Pre Proc Sub Pul Ventricular EF	22	24	2 incorrect	14/15	8/9
25	Pre-proc valve/septal defect/ vessel size	2	6	3 incorrect, 1 absent	2/6	-
26	Consultant	27	27		16	11

	Parameter GUY	**Total Score**	**Total No**	**Comments**	**Scores for Cardiology & Surgery**	
					C	**S**
27	Date of Procedure + Time Start	27	27		16	11
28	Proc Urgency	26	27	1 incorrect	16	11
29	Unplanned Proc	2	2		1	1
30	Single Operator	4	5	1 incorrect	4/5	-
31	Operator 1	25	27	2 incorrect	14/16	11
32	Operator 1 Grade	25	27	2 incorrect	14/16	11
33	Operator 2	19	22	3 incorrect	8/11	11
34	Operator 2 Grade	19	22	3 incorrect	8/11	11
35	Procedure Type	27	27		16	11
36	Sternotomy Sequence	10	11	1 absent	-	10/11
37	Operation Performed	27	27		16	11
38	Sizing balloon used for septal defect	-	-		-	-
39	No of stents or coils	2	2		2	-
40	Device Manufacturer	14	16	1 absent, 1 incorrect	12/14	2
41	Device Model	14	16	1 absent, 1 incorrect	12/14	2
42	Device Serial No	20	22	1 absent, 1 incorrect	20/22	2
43	Device Size	6	10	4 absent	5/8	1/2
44	Total Bypass Time	10	10		-	10
45	XClamp Time,	10	10		-	10
46	Total Arrest	0	1	1 absent	-	0/1
47	Cath Proc Time,	14	16	2 absent	14/16	-
48	Cath Fluro Time,	16	16		16	-
49	Cath Fluro Dose,	14	16	2 absent	14/16	-

	Parameter GUY	**Total Score**	**Total No**	**Comments**	**Scores for Cardiology & Surgery**	
					C	**S**
50	Duration of Post Op Intubation	5	8	3 incorrect	-	5/8
51	Post Procedure Seizures	27	27		16	11
52	Post Proc Complications	7	9	1 absent, 1 incorrect	3/5	4
53	Date of Discharge	27	27		16	11
54	Date of Death	1	1		-	1
55	Attribution of Death	1	1		-	1
56	Status at Discharge	27	27		16	11
57	Discharge Destination	22	27	3 incorrect, 2 absent	13/16	9/11

Data Quality Indicator Assessment:
The Overall Trust DQI GUY = 94.5% Cardiology DQI = 93.5% Surgery DQI = 94.75%

DOMAIN GUY	**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 .94**	
	Card .93	**Surg** .95
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 .93**	
	Card .90	**Surg** .93
Outcome Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination. **Post Procedure Complications.**	**Overall** .91	
	Card .91	**Surg** .91

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. GUY	**2025 24/25 Data**	**2024 23/24 data**	**2023 22/23 combined data**	**2022 21/22 data NHB Score in ( )**
Demographics	1.0	1.0	1.0	1.0 (95)
Pre Procedure	.94	.97	.97	.99 (97)
Procedure	.93	.95	.99	1.0 (95)
Outcome	.91	.98	.99	1.0 (92)

Conclusions

On the whole the NCHDA data for congenital procedures was accurate, well-documented, good quality and was appropriately recorded across the Trust. The Data Quality Indicator Score is 94.5%. This is slightly lower than 2024 (97.5%) but still a good score. The Trust has gone through a large merger with an adjacent Organisation and launched a completely new electronic health system within 3 years. This is the first full year of collecting data in EPIC and amounts to in the region of 2000 procedures. There is a continuing strong commitment to good quality verified clinical data across all of the sites that provide care for and perform procedures for patients with congenital heart disease and there is a very robust culture of clinical audit embedded within the Trust.

The Validation Team would like again, to commend the efforts of both of the CNSs and Analysts, in maintaining this at a time when there have been so many continued infrastructure and location challenges as the two large NHS Trusts have come together.

Also, the external Validation Team would like to thank the Clinical Director and General Manager who made time to spend with them throughout the day.

The Trust has developed and regularly reviews SOPs to inform the congenital data collection which further underpins this registry.

The new Organisation has clearly made a strong early commitment to move to entirely electronic record keeping with EPIC. The Congenital Cardiac Audit Team receive all booked cardiac operating room and catheter lab episodes and this is clearly a huge advantage in ensuring that almost full case ascertainment for NCHDA is achieved whenever possible.

The NHCDA Validation Team note that GSTT are finding some minor issues with data points and these are addressed promptly when identified. For example when a patients' weight is recorded, it appears to replace some or all of the previous weight measurements recorded for that patient.

As in 2024, it was reported to the external Validation Team that engagement of the ACHD clinicians with filling out their NCHDA Smartforms that are part of the EPIC that generates the eventual data submission to the Registry; is still quite poor on occasions with the congenital data management team having to populate the vast majority of the data that cannot be collected automatically within the eHR – (EPCC codes and complications etc).

The EPIC presentation of documentation to the Validation Team connected and generally worked very well. There were occasional dips in verbal clarity and it was occasionally slowed.

As previously observed, the Validation Team note that GUY meet the 2016 NHSE recommendation that in line with the New Congenital Heart Disease Review (NHSE May 2016) recommendation B32(L1); that each Level 1 Paediatric Specialist Congenital Cardiac Surgery Centre must have a minimum of 1.0 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1.0 WTE assistant, responsible for audit and database submissions in accordance with necessary timescales.

The ACHD Specialist Surgical Standards (NHSE May 2016) recommendations state (B33L1) that each Level 1 centre must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales.

This is further underpinned by The Report of the Independent Review of Children's Cardiac Services in Bristol (June 2016 Grey, Kennedy 1.22(2) and Ch17).

However, as the cardiovascular service at this Organisation is now a merger of two very large NHS Trusts, these standards may need to be considered closely to ensure that the changing workload and distribution of procedures in this multi sited provider is adequately reflected and protected with a sufficient number of DBM roles to enable cross site data collection and to quality control the very large amount of NCHDA data that is now generated. High standards of data quality may be compromised without sufficient, well trained and well supported clinical data managers to support not only the NCHDA, but also the various related NHSE monthly and quarterly activity analyses and 'dashboard' requests.

It's always helpful for local host colleagues both to understand the site validation process in general and also to appreciate the accessibility in reverse of their own data systems. Its very important that the diagnosis for instance, reconciles with the procedure performed, this may also affect what ends up in the NCHDA database etc. So particularly for the people doing procedures and entering the data its quite informative. It also very much helps to have some local clinicians around when looking through the notes even when they have been very well collated together as the very complex episodes can be quite hard to follow.

Recommendations for combined GUY and Royal Brompton (GSTT) Service 2025

1. As in 2024, it is recommended that the recently combined congenital cardiac service between Guy's St Thomas's and Royal Brompton Hospital Trusts, consider how to best to meet the New Congenital Heart Disease Review (NHSE June 2016) recommendation B32(L1) and B33 (L1) that each Specialist Surgical Centre must have a minimum of 1.0 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1.0 WTE assistant, and 1.0WTE for ACHD responsible for audit and database submissions in accordance with necessary timescales; or whether this needs to be expanded given the extremely large size of the Organisation and number of congenital cardiac procedures now being undertaken. The individuals currently in post should fulfil dedicated roles to meet the growing demands of the now enlarged, NCHDA data collection and NHSE with no other 'add on' parts.
2. It is recommended that any Standard Operating Protocols (SOP) that support the congenital data collection, should continue to be regularly reviewed to ensure that details are current and clear as to **exactly who** is responsible for;
    a. Input of the data for each procedure and at which point of the service delivery at each of the sites where procedures are performed.
    b. 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
    c. Reverse validation of the data submitted to NCHDA against locally held 'gold standard' clinical information systems in conjunction with clinician colleagues. This encourages ownership of the data.
    d. Leading the local review (and how frequently and in which forum for both disciplines)
    e. Making timely submissions (monthly is recommended) and where possible within 2 weeks of a procedure.
    f. Ensuring operators names and GMC and Name are always submitted.
    g. Careful and consistent descriptions of ventricular function for all procedures in patients with congenital heart disease.
    h. Ensuring the correct units of measurement of radiation are recorded for each procedure. cGy/cm^2 is the measurement required.
    i. Careful and detailed recording of all manufacturers details and serial numbers of implanted devices in the correct NCHDA data fields.
    j. Checking for any out of hospital deaths that may have occurred in the congenital cohort.

   k. Where a patient has died within 30 days of a procedure, documenting whether or not there was a discussion with the Medical Examiner or Coroner (when required), or was discussed at a Mortality and Morbidity review and whether or not the death was related to the procedure as these are NCHDA dataset items. Including a copy of the MCCD in the hospital would be helpful also.
   l. Identifying the responsible clinician for completing the field for Attribution of Death as this should not be a non clinical DBMs responsibility.
   m. Timely reverse validation together with the Clinical Lead(s) for Congenital Cardiology and the responsible clinicians
   n. It is recommended that all staff connected with NCHDA audit should observe at least one other site validation per year.

3. ACHD colleagues should be encouraged to take ownership of and responsibility for their data, to be more pro active and responsive and complete the NCHDA documentation either at the point of service or as soon as possible after the patient contact.
4. 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.