National Congenital Heart Disease Audit

Data Manual

For dataset version 6.1 – January 23 Revision
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Contents

Device

ACHD specific preprocedure status

Cardiac catheterisation procedure and complications

Unique identifier

Coding guidelines and case inclusion

NCHDA data submission: clinical guide on the definition of "congenital"

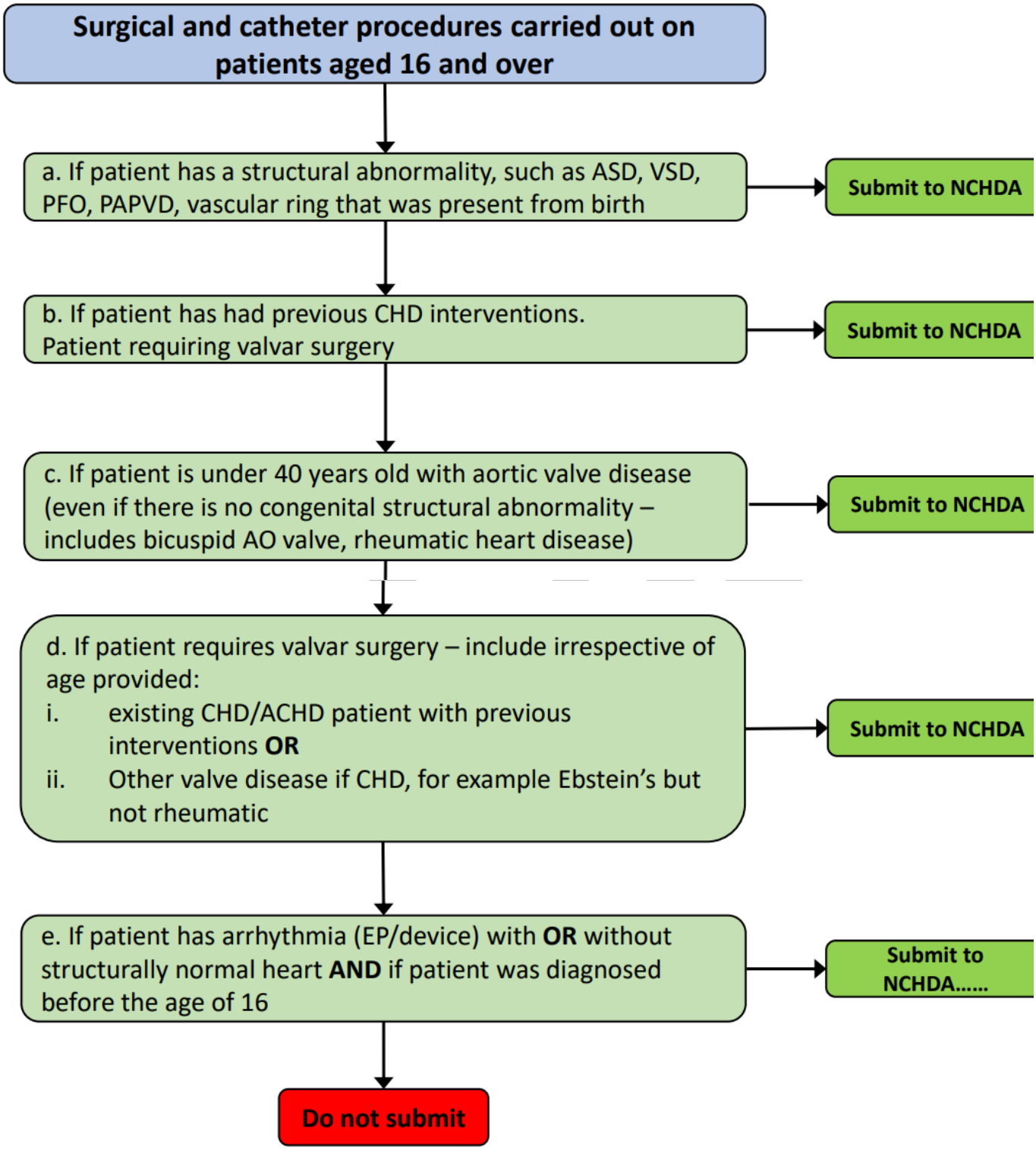
Paediatric cardiac surgical or interventional procedures are defined as any cardiac or intrathoracic great vessel procedure carried out in patients under the age of 16 years.

Adult congenital cardiac procedures are defined as those performed for a cardiac defect present from birth. This does NOT include surgery or therapeutic catheterisation for degenerative disease such as aortic aneurysm or dissection or mitral valve surgery even if associated with hereditary conditions such as Marfan's syndrome or other connective tissue diseases. Aortic valve disease requiring treatment in adult life is always a dilemma, as many patients have had some aortic valve anomaly from birth. As suggested by the SCTS some years ago, it seems reasonable to suggest that as a general practical cut-off patients under the age of 40 years who have aortic valve procedures should be regarded as having congenital heart disease but those over the age of 40 should be regarded as having degenerative valve disease unless they have had previous treatment for aortic stenosis during childhood.

Patent foramen ovale (PFO) is present from birth and transluminal PFO closure therefore falls within the remit of the National Congenital Audit (NCHDA).

Patients with degenerative cardiac disease who have a surgical closure of a PFO in addition to undergoing other procedures such as valve replacement do not need to be submitted to NCHDA.

All paediatric and adult congenital procedures should be submitted to the National Congenital Audit, others to the relevant adult national clinical audit databases.


Surgical and catheter procedures carried out on patients aged 16 and over
a. If patient has a structural abnormality, such as ASD, VSD, PFO, PAPVD, vascular ring that was present from birth
Submit to NCHDA
b. If patient has had previous CHD interventions. Patient requiring valvar surgery
Submit to NCHDA
c. If patient is under 40 years old with aortic valve disease (even if there is no congenital structural abnormality – includes bicuspid AO valve, rheumatic heart disease)
Submit to NCHDA
d. If patient requires valvar surgery – include irrespective of age provided:
i. existing CHD/ACHD patient with previous interventions OR
ii. Other valve disease if CHD, for example Ebstein's but not rheumatic
Submit to NCHDA
e. If patient has arrhythmia (EP/device) with OR without structurally normal heart AND if patient was diagnosed before the age of 16
Submit to NCHDA……
Do not submit

1.00 Dataset version

Description	The version of the dataset the data was collected for and submitted to NICOR
Reason	Important for ensuring the interface in Lotus Notes and the Web version show the correct data controls. For determining completeness of submitted data and for restricting data to permitted values and format.
Format	Text (single value)
Values & definition	4.09, 5.10, 5.12 : current version 6.10 November 2019 Revision
Validation	Not validated
Other	

1.01 Hospital identifier

Description

The identifier allocated to the hospital by NICOR. Used for identification and analysis of individual centre data. Valid Hospital identifiers are listed in a separate file. The software should set this field without any user involvement.

Reason

To identify the data submitted by each centre within the database

Format

Text (single value)

Values & definition

Valid codes:

ACH	ACH. Liverpool - Alder Hey Hospital
BCH	BCH. Birmingham Children's Hospital
BHL	BHL. Liverpool - Heart and Chest Hospital
BRC	BRC. Bristol Royal Hospital For Children
CHN	CHN. Nottingham City Hospital
FRE	FRE. Newcastle - Freeman Hospital
GEO	GEO. London - St George's Hospital
GJH	GJH. Glasgow - Golden Jubilee National Hospital
GOS	GOS. London - Great Ormond Street Hospital for Children
GRL	GRL. Leicester - Glenfield Hospital
GUY	GUY. London - Evelina Children's Hospital
HAM	HAM. London - Hammersmith Hospital
HSC	HSC. London - Harley Street Clinic
LGI	LGI. Leeds General Infirmary
MRI	MRI. Manchester Royal Infirmary
NCR	NCR. Wolverhampton Heart & Lung Centre
NGS	NGS. Sheffield - Northern General Hospital
NHB	NHB. London - Royal Brompton Hospital
OLS	OLS. Dublin - Our Lady's Children's Hospital
QEB	QEB. Birmingham - Queen Elizabeth Hospital
PAP	PAP. Papworth Hospital
RAD	RAD. Oxford - John Radcliffe Hospital
RHS	RHS. Glasgow - Royal Hospital for Sick Children
RSC	RSC. Brighton - Royal Sussex County Hospital
RVB	RVB. Belfast - Royal Victoria Hospital
SBH	SBH. London - Barts Heart Centre
SGH	SGH. Southampton University Hospital
UHW	UHW. Cardiff - University Hospital of Wales
VIC	VIC. Blackpool Victoria Hospital
WAL	WAL. University Hospital Coventry

Validation

Exact match

Other

1.02 Patient case record number

Description Patient's hospital record number

Reason The permanent number for identifying the patient across all departments within the hospital. The NICOR Hospital identifier and this field are used to link records from the same hospital for the same patient. Separate episodes for the same patient will not be linked correctly unless the permanent identifier for the patient is used.

Format Free text

Values & definition NA

Validation Exact match

Other

PRAiS Used to determine multiple procedures within the 30-day surgical window

1.03 NHS number

Description

Unique national identifier for patient. If the NHS Number is not included in the record, NICOR will attempt to obtain it from the National Strategic Tracing Service (NSTS) using the patient's name, date of birth and postcode. The Scottish Community Health Index (CHI) number should be included in this field where applicable as this is now used as a tracing tool in Scotland. For Northern Ireland the Health and Social Care (HCNI) Number should be included in this field.

Reason

NICOR uses the NHS number for English and Welsh patients to:

(1) Make regular enquiries on the patient's status, and in particular, to obtain the patient's date of death

(2) To link records for the same patient from different hospitals.

The CHI number in Scotland has been developed to work in a similar way and the HCNI number is being developed to work in this way for Northern Ireland

For export purposes please remove all spaces between numbers.

Format

10 digit (no spaces) valid NHS/CHI/HCNI Number

Values & definition

1111222233

Validation

Exact match

Other

1.04 Patient surname

Description	Surname as it appears on the patient's case notes, labels and documentation
Reason	Surname provides an additional identifier that can aid patient tracking
Format	Text single value (upper case)
Values & definition	SMITH
Validation	Exact match
Other	

1.05 Patient forename

Description	Forename as it appears on the patient's case notes, labels and documentation
Reason	Forename provides an additional identifier that can aid patient tracking
Format	Text single value (Use upper case for first letter of each forename, lower for remainder)
Values & definition	James
Validation	Exact match
Other	

1.06 Patient date of birth

Description	The patient's date of birth as recorded on the case notes
Reason	Date of birth and Date of procedure are used to calculate age at operation. Date of birth provides an additional identifier that can aid patient tracking.
Format	Day, month, four digit year. 28/12/2001. No other format acceptable. Valid date >1880 and <=Today
Values & definition	dd/mm/yyyy
Validation	Exact match
Other	
PRAiS	Used to determine age: only children (<16) included

1.07 Patient gender

Description Identifies the genotypical sex of the patient.

Reason Gender provides an additional identifier that can aid patient tracking.

Format Text (single value)

Values & definition
0. Not known
1. Male
2. Female
9. Not specified

Validation Exact match

Other

1.08 Patient ethnic group

Description Identifies the patient's ethnic origin.

Reason Potentially of value in clinical audit and research in conjunction with other clinical data.

Format Text (single value)

Values & definition Ethnicity values use the standard NHS list for ethnicity:

A. White - British
B. White - Irish
C. White - Any other White background
D. Mixed - White and Black Caribbean
E. Mixed - White and Black African
F. Mixed - White and Asian
G. Mixed - Any other mixed background
H. Asian - Indian
J. Asian - Pakistani
K. Asian - Bangladeshi
L. Asian - Any other Asian background
M. Black - Caribbean
N. Black - African
P. Black - Any other Black background
R. Other - Chinese
S. Other - Any other ethnic group
Z. Not stated
9. Unknown

Format expected:
G. Mixed - Any other mixed background

Validation Exact match

Other

1.09 Patient admin status

Description	Type of admission, i.e. from UK public health service or other mode of entry to the service
Reason	To understand demand on the service
Format	Text (single value)
Values & definition	1. NHS 2. Private 3. Amenity 4. Overseas charity 9. Unknown 'Amenity Patient' is one who pays for the use of a single room or small ward in accordance with the National Health Service Act 2006. Some NHS patients are treated at private hospitals because of capacity issues – these should be coded as NHS patients.
Validation	Exact Match
Other	

1.10 Patient postcode

Description The postcode for the patient's normal place of residence.

Reason Postcode provides an additional identifier that can aid patient tracking.

Can help identify patients who may have had multiple procedures in one or more centres.

Postcode provides a means of linkage to geographic and demographic information.

Format The NHS standard requires the use of the full post code. For patients whose main residence is abroad, please use the NHS standard pseudo-postcode

Values & definition

Postcode: PO1 3AX
PO the area. There are 124 postcode areas in the UK
1 the district. There are approximately 20 Postcode districts in an area
3 the sector. There are approximately 3000 addresses in a sector.
AX the Unit. There are approximately 15 addresses per unit.

The following list shows all valid Postcode formats. "A" indicates an alphabetic character and "N" indicates a numeric character.

Format	Example
AN NAA	M1 1AA
ANN NAA	M60 1NW
AAN NAA	CR2 6XH
AANN NAA	DN55 1PT
ANA NAA	W1A 1HQ
AANA NAA	EC1A 1BB

Validation Exact match

Other

2.01 Diagnosis

Description

The preprocedural diagnosis of the patient

Reason

Avoid unnecessary coding of normal aspects of anatomy (e.g. do not code situs solitus, only code situs if it is abnormal).

Relevant previous operations or interventions should not now be coded here but in the next metric, as of April 2015.

Primary diagnosis should reflect the main intended therapeutic procedure regardless of whether procedure carried out successfully or failed.

Format

Text (multivalue ; separated) (The 'short' format should be used i.e. only the 6 digit code for QREG5 upload)

Any previous procedures should be in the previous procedures field and comorbidity codes should be in the comorbidity field.

Note: There are different comorbidity code lists (PRAiS uses a selected different list based on these): current list

Values & definitions

Example: 010106. Pulmonary atresia + ventricular septal defect (VSD) (including Fallot type)

Multiple diagnoses separated by a ;

Example: 010106. Pulmonary atresia + ventricular septal defect (VSD) (including Fallot type); 091011. Pulmonary arterial hypoplasia. In CSV file this should be 010106; 091011.

If the patient has had, for example, a pacemaker implanted there should be a corresponding diagnosis for the reason e.g. '110633. Postprocedural complete atrioventricular block requiring permanent pacemaker system'

Validation

Main diagnosis must be exact, but minor additional diagnoses are unnecessary e.g. ASD, PDA, are unimportant if there is a major diagnosis listed as well (such as VSD, tetralogy of Fallot or interrupted arch).

Other

PRAiS

First 6 diagnostic codes are used in PRAiS2 to determine univentricular heart status (UVH), diagnostic group and additional risk factors – severity of illness (SOI), acquired cardiac risk, acquired comorbidity and congenital comorbidity. The order is not important as long as key diagnoses are within the first 6 codes, as PRAiS looks at these and then matches them with its own hierarchy to attribute to correct group.

PRAiS2 (and 1) looks in diagnosis and comorbidity (dataset items 2.10 & 2.07) for the appropriate codes.

Diagnosis is categorised:
Note: the final diagnosis risk category for a surgical episode is calculated by:

1) assigning the episode the highest ranking diagnosis group for all entered diagnostic codes (column C).
2) Using the mapping assigned from overall diagnosis group to a broad diagnosis risk grouping in column D (which is then used in the PRAiS risk model)

Note: If any diagnosis code in an episode is a definite indication of Univentricular heart function then the UVH flag for that episode is set to 1. Additionally, the UVH flag is set to 1 if the specific procedure is Norwood, Fontan or Bidirectional cavopulmonary shunt or there is other procedural information specifying that the patient must be UVH (see procedure sheet)

Please see Brown et al. CiTY, 2013 23(4):491-8 for more information on how these diagnostic groupings were originally developed.

See the file downloaded as part of the PRAiS software called 'Important_Mappings_Used_For_PRAiS_v3_0_2.xlsx' and the 'Diagnosis' worksheet.

Note: NCHDA uses the Association for European Paediatric and Congenital Cardiology derived version of the International Paediatric and Congenital Cardiac Code (www.ipccc.net), whose derived Short List is known as the European Congenital Cardiac Code."

2.02 Previous procedure

Description Relevant previous procedures

Reason Relevant previous operations or interventions should be coded here, as of April 2015. AEPC (EPCC) diagnostic coding should be used and has been in use since 1st April 2003, with rejection of other codes in force since 1st April 2004. For data export purposes multiple values should be separated using semicolons.

Format Text (multivalue ; separated) (The 'long' format should be used)
The previous procedures should appear in the order they were performed and if multiple procedures with the same code are performed then they should appear multiple times in chronological order.

Procedures that would not normally be counted/submitted should not be included – for example minor or excluded procedures.

Values & definitions

123111. Bidirectional superior cavopulmonary (Glenn) anastomosis

Multiple previous procedures separated by a ;

123111. Bidirectional superior cavopulmonary (Glenn) anastomosis; 121420. Pulmonary arterioplasty/ reconstruction

Procedures that would be classified as 'Minor and Excluded Procedures' or diagnostic procedures should not be included e.g.

123280. Insertion of pleural tube drain
130501. Diagnostic catheterisation procedure

Validation Exact match

Other

2.03 Weight

Description The patients weight in kg at the time of procedure to two decimal places.

Reason Risk indicator

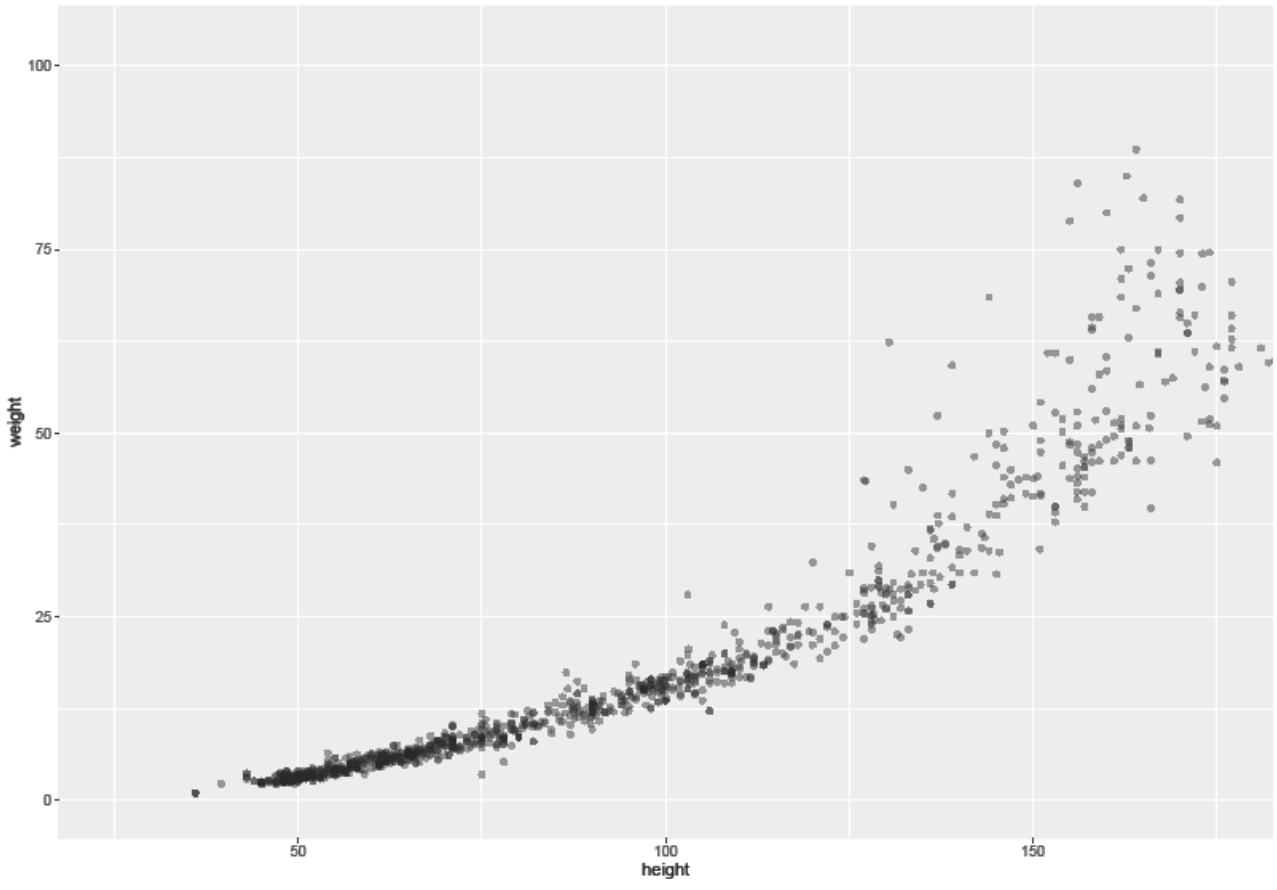
Format Weight in Kg at the time of the procedure, to two decimal places.

Values & definitions 0.95 kg, 26.50 kg

Validation Should be within +/- 5% if age under 5 years, within +/- 10% if older than that. If more than one weight recorded in medical records the weight recorded on the anaesthetic sheet should be submitted and this would be the value used for data validation.

Other It is good practice to plot height vs weight during data validation or use 3D plot for age vs height vs weight to identify unlikely/inconsistent values for checking.

PRAiS Weight is used in PRAiS v1 & v2



2.03b Height

Description	Height at time of procedure in cm
Reason	Risk indicator
Format	Integer value
Values & definitions	70, 125 This is only required for patients 2 years of age and older.
Validation	Within +/- 5%
Other	It is good practice to plot height vs weight during data validation or use 3D plot for age vs height vs weight to identify unlikely or impossible values

2.04 Antenatal diagnosis

Description Diagnosis detected prior to birth from prenatal scans

Reason Supports service planning and intervention

Format Text (single value)

Values & definitions

1. Yes
2. No
9. Unknown

Note: this isn't used to assess the accuracy of the antenatal diagnosis but only to indicate whether a heart abnormality was detected antenatally.

Patent ductus arteriosus (PDA), patent foramen ovale (PFO) or atrial septal defect (ASD) are not diagnosed antenatally.

Validation Exact match

Other

2.05 Preprocedure seizures

Description Any preprocedural convulsions/seizures requiring medication

Reason Base line status and can be a risk indicator

Format Text (single value)

Values & definitions

1. Yes
2. No

Validation Exact match

Other Pre-procedure seizures requiring any kind of medication. If the patient is on medication(s) for seizures you should enter 'Yes' irrespective of whether they are currently having seizures or not. For febrile convulsions or other seizure activity that does not require medication 'No' should be reported.

2.06b Comorbidity present

Description A comorbidity is the presence of one or more additional disorders (or diseases) co-occurring with a primary disease or disorder; or the effect of such additional disorders or diseases.

Reason Base line status and can be a risk indicator

Format Text (single value)

Values & definitions

1. Yes
2. No

Only answer 'Yes' if the comorbidity is on the current dataset list or a significant other comorbidity is present (please describe), there are other comorbidities that are present in the list of diagnoses that are not in the comorbidity list.

Note: The NCHDA list does not match the PRAiS2 'Additional Risk Factors' list.

Validation Exact match

Other

2.07 Comorbid conditions

Description Identifies the specific comorbid condition

Reason Needed for base line status and risk assessment and may be part of Partial Risk Adjustment in Surgery (PRAiS) analysis.

Format Text (multivalue ; separated) (The 'long' format should be used)

Values & definitions

102014. Preprocedural mechanical ventilatory support

102202. Premature birth

140219. Noonan syndrome

140305. Psychomotor developmental delay

140359. Obesity (Body Mass Index over 30)

Validation Exact match

Other

PRAiS PRAiS2: the presence/absence of any comorbidity has been expanded in v2 to include: additional risk factors – severity of illness (SOI), acquired cardiac risk, acquired comorbidity and congenital comorbidity.

Note: PRAiS2 will pick up comorbidities whether in the diagnosis or comorbidity field – but note that not all diagnostic/comorbidity codes are used in PRAiS2:
Codes that fall outside the first 6 diagnostic codes will not score and codes that fall outside the first 8 comorbidity will not score.

NCHDA comorbidity list
Note: The NCHDA list does not match the PRAiS2 'Additional Risk Factors' list.

2.08 Preprocedure systemic ventricular function

Description Categorises the percentage of the blood emptied from the systemic ventricle at the end of the contraction. Data may have been derived from angiography, echocardiography, nuclear imaging, magnetic resonance imaging etc. **Use this metric to define ventricular function in patients with functionally single ventricle anatomy.**

Reason Base line measure and risk indicator

Format Text (single value)

Values & definitions

1. Good
2. Moderate
3. Poor
9. Unknown

Fractional shortening (FS): is the degree of shortening of the ventricular diameter between end-diastole and end-systole.

Ejection fraction (EF): is the percentage of the blood emptied from the systemic ventricle at the end of the contraction. Data may have been derived from angiography, echocardiography, nuclear imaging, magnetic resonance imaging etc.

Good:	EF >50%	FS > 28%
Moderate:	EF 30 – 50%	FS 15-28%
Poor:	EF 15 – 29%	FS < 15%

Validation Exact match with angiography/echo/imaging/MRI reports.
If no numerical objective value is present, designation of good, moderate or severe dysfunction is acceptable, when categorisation is based on a subjective assessment only ('eye-balling'). This is not uncommon in poorly cooperative small children or infants.

Other

PRAiS Version 2 includes:

070111. Right ventricular dysfunction
070610. Left ventricular dysfunction

As additional risk factors but note these should only be used if: EF <30%; FS <15% = poor function (i.e. severe dysfunction).

2.09 Preprocedure subpulmonary ventricular function

Description Categorises the percentage of the blood emptied from the subpulmonary ventricle at the end of the contraction. Data may have been derived from angiography, echocardiography, nuclear imaging, magnetic resonance imaging etc. **Do not use this metric for patients with functionally single ventricle anatomy or pathway of treatment**, i.e. when the sub-pulmonary LV or RV is significantly hypoplastic, the '4. Not applicable' category should be entered. It is acknowledged that this can be a marginal decision, such as with double outlet RV.

Reason Base line measure and risk indicator

Format Text (single value)

Values & definitions

1. Good
2. Moderate
3. Poor
9. Unknown

Ejection fraction (EF): is the percentage of the blood emptied from the subpulmonary ventricle at the end of the contraction. Data may have been derived from angiography, echocardiography, nuclear imaging, magnetic resonance imaging etc.

Function can be assessed using: Ejection fraction (EF) (usually MRI derived: percentage of blood emptied from the sub-pulmonary ventricle at the end of the contraction); Fractional Area Change (usually echo derived: calculated % difference in end-diastolic area and end-systolic area, divided by the end-diastolic area); angiography; or nuclear imaging.

Good :	EF >50%	FAC >35%
Moderate :	EF 30 – 50%	FAC 30-35%
Poor :	EF 15 – 29%	FAC <30%

Validation Exact match with angiography/echo/imaging/MRI reports.
If no numerical objective value is present, designation of good, moderate or severe dysfunction is acceptable, when categorisation is based on a subjective assessment only ('eye-balling'). This is not uncommon in poorly cooperative small children or infants.

Other

PRAiS Version 2 includes:

070111. Right ventricular dysfunction
070610. Left ventricular dysfunction

as additional risk factors but note these should only be used if: EF <30%; FS <15%; FAC < 30% = poor function (i.e. severe dysfunction).

3.01 Date/Time procedure

Description	Records the actual date and start time of procedure
Reason	To analyse resources used, measure procedure timing and risk stratification
Format	Valid date and time
Values & definitions	DateTime (dd/mm/yyyy hh:mm) 22/04/16 16:20
Validation	Exact match with operation record and/or anaesthetic record
Other	Use the 'knife to skin' time as the start time of the operation, for cardiac catheters use the time of starting to gain vascular access. Should not include draping and skin preparation.
PRAiS	Used to determine age at operation and to identify deaths within 30 days of the operation.

3.01b Procedure urgency

Description Categorises the patient in terms of the urgency

Reason Can be used to identify patients at particularly high risk i.e. patients whose condition cannot be optimised prior to the procedure.

Format Text (single value)

Values & definitions

1. Elective
2. Urgent
3. Emergency
4. Salvage

Elective: Routine admission from the waiting list.

Urgent: Patients who have not been scheduled for routine admission from the waiting list but who require intervention or surgery on the current admission for medical reasons. They cannot be sent home without procedure.

Emergency: Unscheduled patients with ongoing cardiovascular compromise or hypoxia. Requirement for procedure within 24 hours irrespective of the time of day.

Salvage: Patients in imminent risk of demise without intervention. Includes arrest requiring active cardiopulmonary resuscitation en route to the operating theatre or prior to the induction of anaesthesia. CPR following anaesthetic induction should not be included.

Validation Exact match

Other

3.01c Unplanned reoperation

Description Used to identify cases that aren't part of the planned pathway for that patient.

Reason Can be used to assess the need for unplanned procedures and may be a risk factor.

Format Text (single value)

Values & definitions

1. Yes
2. No

Validation Exact match

Other

Select 'Yes' if fits the definition below:

Unplanned re-operations are procedures outside the expected patient pathway which may be undertaken at any time from the start of the postoperative admission up until 30 days following the primary operation.

Unplanned re-operations may be cardiac bypass, cardiac non-bypass, pacemaker placement (lead revision/repositioning), interventional catheterisations or diaphragm plication (as per NHSE inclusion in SSQD).

Unplanned re-intervention cannot be elective by definition.

Select 'No' if fits one of the following scenarios:

- Not a re-intervention within 30-days (if there is no other countable procedures within 30-days prior to unplanned procedure).
- Staged intervention – for example septostomy followed by arterial switch (neither of which are elective)
- Planned re-intervention (patient admitted for catheter intervention with subsequent planned surgery – stenting of pulmonary artery followed by Fontan – needs to be documented). These should both be elective.
- Additional procedures or revisions undertaken within the primary trip to the operating theatre (incorporating return onto cardiopulmonary bypass) are not included in the definition of re-operation. (However, patients that have, for example, a failed catheter device implantation followed by an urgent device removal (surgical) should be entered as 2 procedures and the second should be an unplanned re-operation).
- The definition does not include procedures for bleeding, closure of chest, support (ECLS/ECMO) or other non-cardiac surgery procedures or other non-bypass cardiac procedures that would be classified in the 'Minor and Excluded

Procedures' procedure type – these are not counted as unplanned re-operation irrespective of the urgency.

3.02 Consultant Responsible for Procedure

Description	The consultant responsible for the procedure
Reason	Identifies the consultant clinician responsible for the procedure
Format	Text (single value)
Values & definitions	Should be in the format initial(s) and surname e.g. J.Smith Note: it is optional to prepend the GMC code before the name.
Validation	Exact match
Other	The consultant responsible would normally be either the first operator or first assistant but that may not be the case. It shouldn't be interpreted as the 'administrative' consultant for the patient's care i.e. the spell/episode consultant.

3.02c Single operator/dual consultant procedure

Description	Procedure carried out without an assistant or second operator
Reason	Single operator procedures may add to clinical risk and indicate staffing deficiencies and training opportunities that are not being used.
Format	Text (single value)
Values & definitions	1. Single operator 2. Consultant and trainee (junior) doctor 3. Planned two consultant case (preprocedural decision) due to case complexity 4. Second consultant present due to intraoperatively found complexity/complication 5. Second consultant for training/mentorship
Validation	Exact match
Other	This is to identify where there is no assistant and does not mean only the first operator performing the whole procedure. If this is 'yes' then the first assistant should be blank. Consutant can only be recorded as one of the operators if scrubbed and taking part in the procedure, not when they are present for advice or a TOE. Where second consultant joins a procedure which already involves 1st consultant and an SpR, the 2nd consultant should be reported to NICOR as 2nd operator taking precedence over the SpR.

3.03 First operator

Description	The main operator for the procedure
Reason	Can be used to identify individual activity and assess the exposure to cases for clinicians in training
Format	Text (single value)
Values & definitions	Should be in the format initial(s) and surname e.g. J.Smith Note: it is optional to prepend the GMC code before the name.
Validation	Exact match
Other	This should be the operator doing the main part of the procedure

3.04 First operator grade

Description First operator, either performing part of the procedure or assisting

Reason Can be used to identify dual consultant cases, procedures performed by clinicians in training and levels of supervision

Format Text (single value)

Values & definitions

1. Consultant
2. Staff grade/Clinical Assistant
3. SpR
5. SHO
6. Associate specialist
7. Surgeon's assistant
9. Other

Validation Exact match

Other

3.05 First assistant

Description	This should be the clinician performing part of the procedure or assisting with the procedure
Reason	Can be used to identify individual activity and assess the exposure to cases for clinicians in training
Format	Text (single value)
Values & definitions	Should be in the format initial(s) and surname e.g. J.Smith Note: it is optional to prepend the GMC code before the name.
Validation	Exact match
Other	This should be either the person assisting or the person doing part of the procedure. They must be scrubbed and actively participating in the operation.

3.06 First assistant grade

Description The grade of the secondary operator or assitant

Reason Can be used to identify dual consultant cases, procedures performed by clinicians in training and levels of supervision

Format Text (single value)

Values & definitions

1. Consultant
2. Staff grade/Clinical Assistant
3. SpR
5. SHO
6. Associate specialist
7. Surgeon's assistant
9. Other

Validation Exact match

Other Where 2nd consultant joins a procedure which already involves 1st consultant and an SpR, the 2nd consultant should be reported to NICOR as 2nd operator taking precedence over the SpR.

3.07 Type of Procedure

Description Defines the group the procedure should be included in.

Reason Used on the portal to categorise activity levels

Format Text (single value)

Values & definitions

1. bypass
2. non-bypass
3. catheter intervention
4. thoracic
5. diagnostic catheter
6. support
7. hybrid
8. other
9. not known
10. electrophysiology - catheter
11. electrophysiology - surgery

Validation Exact match

Other

1. **bypass** – any case where cardiopulmonary bypass is employed during a surgical procedure – this does not include cross clamping of the aorta when repairing a coarctation of the aorta.
2. **non-bypass cardiac surgery**: any cardiac surgery performed without the use of bypass (includes operations involving the great vessels) e.g. aortopexy, repair of vascular ring, PDA ligation.
3. **catheter intervention**: include device closure or embolisation of defects or vessels, stenting or ballooning of vessels. If a procedure is attempted but fails then include code as a failed intervention '124136. Therapeutic cardiovascular catheter procedure with failed attempt to deploy device-stent-coil' and classify as '3. Catheter intervention' but only if the device was used but not deployed successfully (the device needs to have been introduced into the body). Do not include as an intervention if for example you could not cross a lesion or you assess an ASD by TOE and decide not to carry on and close it. These procedures should be coded as '130536. Diagnostic cardiovascular catheterisation procedure with intention to treat: anatomy unsuitable'. Do not include test occlusions to assess haemodynamics or pulmonary hypertension tests or haemodynamic challenges. Removal of CVL tip (or Broviac) should be classed as an intervention if a snare or other

retrieval method is used. Minor procedures such as placement of central venous lines, chest drain insertions are not counted as catheter interventions.

4. **thoracic**: Surgery to thoracic non-vascular structures – lungs, thoracic duct, diaphragm plication, exploration for mediastinitis, surgery for pectus. Does not include – wound debridement, sternal wire removal and minor/excluded procedures.
5. **diagnostic catheter**: diagnostic left/right heart (or other vessels), including test occlusion of defect, pulmonary vascular resistance (PVR) study and catheterisation procedure with haemodynamic alteration (challenge). Transluminal biopsies (LV, RV other) should be classed as diagnostic. Include cases where there is an intention to carry out catheter intervention which does not happen for some reason, such as inability to get a guide wire across the defect. Device/stent is NOT introduced into the patient. Only diagnostic procedure is carried out. Procedure code should be '130536. Diagnostic cardiovascular catheterisation procedure with intention to treat: anatomy unsuitable' and procedure type should be '5. Diagnostic catheter'.
6. **support**: ECLS/ECMO/VAD cannulation/decannulation. If other procedures carried out at the same time (duct ligation, conduit revision then this should take precedence). You should include VAD removal but not takedown of ECLS/ECMO which should be classified as 8. other.
7. **hybrid**:
    a. **Core definition**. The procedure has a part performed by a cardiologist (intervention not diagnostic) and a part by a surgeon, under the same anaesthetic. Surgical incision to gain access for a cardiology intervention counts as a hybrid. This is a single procedure and should only be submitted once to NCHDA, despite having both surgical and interventional cardiology components.
    b. The cardiology intervention does not need to be a transluminal intervention - some valves or stents may be implanted using surgical access, as may a device (for example a VSD device deployed by a cardiologist) under direct (open) vision.
    c. If during a planned procedure it becomes apparent that an alternative strategy is required and is undertaken (a surgical VSD closure turns out to require an open VSD device deployed by a cardiologist), then this should be coded as a hybrid procedure.
    d. **Exclusions**. Diagnostic catheters; exit angiography; cases in the minor and excluded list (see data manual); and peripheral or carotid access cutdowns.
    e. **EP & pacemaker procedures**: Neither part can be a pacemaker/ICD of other electrophysiology procedure; if it is then the procedure isn't a hybrid and should have a different procedure type assigned. EP (diagnostic or with ablation) is excluded as a valid catheter component of a hybrid.
    f. The procedure can take place in theatre, cath lab , hybrid theatre or hybrid cath lab. The procedure can be undertaken in 2 locations - an

interventional catheter (for example stenting of pulmonary artery) in a cath lab followed immediately by a Fontan procedure in theatre.

g. **Procedures undertaken to deal with a complication**. If one part of the procedure has been precipitated by a complication (for example a planned transluminal ASD closure where the device embolised and cannot be retrieved) requiring emergency intervention (surgical removal of device followed by surgical closure of the ASD) then this should be counted as 2 procedures, and not a Hybrid procedure, (with an appropriate complication code - '159095. Requirement for bail out surgical procedure following procedural complication'). The urgency/planned status for the procedures would then be elective planned, followed by emergency unplanned.

h. **ECMO/ECLS procedures**. These are excluded, whether pre- or post-procedure, the latter usually being entered into the database as a complication.

i. **Hybrid pathway procedures**. These do not always qualify as hybrid procedures - for example a patient may have hybrid palliation for HLHS that includes PDA stenting and bilateral PA banding - however if these are done on different days then neither qualifies as a hybrid procedure type.

j. **Operators**. In the vast majority of cases there will be a consultant surgeon and a consultant cardiologist - these can be coded correctly in the single operator field (3. Planned two consultant case (preprocedural decision) due to case complexity). If a senior SpR undertakes either of these roles then they should be correctly coded and reported (2. Consultant and trainee (junior) doctor) - it is important to know when SpRs are gaining experience in these procedures and coding as if they are dual consultant operator would be misleading.

8. **other**: Use for minor procedures or for procedures that end up in the 'Minor and Excluded Procedures' specific procedure allocation process that are not elsewhere classified. Reopening of the sternum for bleeding or suspected tamponade, drainage of wound, insertion chest drain or pericardial drain. Wound debridement, prominent sternal wire removal. Placement/removal of loop recorder.
9. **not known**: rarely if ever should you use this category.
10. **electrophysiology - catheter**: including EP study with/without ablation, insertion defibrillator, pacemaker insertion (including box change) or pacemaker lead procedures (insertion, repositioning or extraction); will mainly be endocardial. This includes all isolated cardiology procedures relating to pacing or arrhythmia with the exception of the placement/removal of loop recorders (Reveal) are excluded and should be coded as '8. Other'.
11. **electrophysiology-surgery**: including isolated Maze procedures, insertion defibrillator, pacemaker insertion (including box change) or pacemaker lead procedures (insertion, repositioning or extraction); these will mainly be epicardial. This includes all isolated surgical procedures relating to pacing or arrhythmia.

Note: if you do an intervention and pacemaker then the case should be coded as '3' or '1' or '2' as appropriate. Only isolated electrophysiology type procedures should be categorised as 10 or 11.

For PRAiS procedure type 10 should be changed to 3 and for 11 changed to 2.

3.08 Sternotomy sequence

Description

Incremental count of the number of sternotomies that the patient has undergone.

Reason

To identify patients that might be at higher risk.

Format

Text (single value)

Values & definitions

0. Not a sternotomy
1. First sternotomy
2. Second sternotomy
3. Third sternotomy
4. Fourth sternotomy
5. Fifth sternotomy
6. Sixth or more sternotomy

A zero would indicate that an approach other than sternotomy has been used.

Validation

Exact match

Other

This should include all the sternotomies the patient has undergone – if a patient has had a first procedure at another centre it should be included in the sequence. When there have been repeat procedures whilst the chest is still open these should not be counted as additional sternotomies. Additional sternotomies immediately after a surgical procedure for relief of tamponade or bleeding should not be included as additional sternotomies.

3.09 Operation performed

Description

The EPCC short codes that describe the procedure

Reason

Used for allocating cases to the appropriate specific procedure.

Format

Text (multivalue ; separated)

It is preferable to upload 6 digit code only. If the term (wording) after the EPCC code is included it must be an exact match of the wording in the dataset.

Values & definitions

Example 1: 123456 For multiple codes: 123456;123456;123456
Example 2: 123111. Bidirectional superior cavopulmonary (Glenn) anastomosis;121420. Pulmonary arterioplasty/reconstruction

From EPCC short code list (see: https://nicor4.nicor.org.uk/chd/an_paeds.nsf/vwContent/Technical%20Information?Opendocument for current dataset).
The procedures should be coded in the order of magnitude the primary procedure being first.
Be brief and to the point. This is particularly important when using EPCC coding (i.e. IPCCC Long List with software mapping to EPCC before NCHDA submission) e.g. for arterial switch, do not include codes for PDA ligation or ASD closure as they are part of any switch operation.

Codes '130515. Transcatheter procedure undertaken with magnetic resonance imaging guidance' and '130516. Transcatheter procedure undertaken with x-ray & magnetic resonance imaging guidance' should not be used in isolation because they do not map to activity algorithm or specific procedure algorithm. There must be at least one other valid procedure code.

Validation

Exact match

Other

Used to allocate the procedure into one of the specific procedures (this allocation is used for inclusion in the funnel plots). There is a list of minor and excluded (ignored) procedures see

Note: when coding hybrid procedures (for univentricular palliation) it is of the utmost importance that you use the following codes along with any specific procedure details you code. This is because determining what a hybrid is very difficult using the approach used by the current Specific Procedures algorithm.
122021. Hypoplastic left heart syndrome hybrid strategy (transcatheter & surgery)

122020. Hypoplastic left heart syndrome hybrid approach (transcatheter & surgery): stage 1

PRAiS

Version 2: used to categorise the procedure into one of the specific procedure groups (1..15 & 20) and to identify univentricular heart status. The procedure allocation is defined in the files downloadable as part of the PRAiS2 software from UCL and are listed in the 'Important_Mappings_Used_For_PRAiS_v3_0_2.xlsx' on the 'SpecificProcedures' worksheet.

3.10 Total bypass time

Description	The total duration of cardiopulmonary bypass used during the procedure.
Reason	Can be used as a risk factor and to identify procedures where technical difficulties occurred.
Format	Numeric (integer)
Values & definitions	Cumulative total of bypass duration, in minutes, for the whole operation. If there is a period of circulatory arrest this should be included in the total bypass time as well as recorded in the cross clamp time. If there is a period of selective antegrade cerebral perfusion (SACP) it should also be included in the total bypass time. For example, where bypass starts at 10:00 ends at 10:30, cerebral perfusion starts at 10:30 ends at 11:00, then bypass re-starts at 11:00 and ends at 11:30 – 90 minutes of bypass should be recorded.
Validation	Exact match according to perfusion record.
Other	

3.11 Total bypass cross clamp time

Description	The total duration of aortic cross clamp during the procedure.
Reason	Can be used as a risk factor and to identify procedures where technical difficulties occurred.
Format	Numeric (integer)
Values & definitions	Cumulative total of cross clamp duration, in minutes, for the whole operation.
Validation	Exact match according to perfusion record.
Other	

3.12 Total circulatory arrest time

Description	The total duration of circulatory arrest during the procedure.
Reason	Can be used as a risk factor and to identify procedures where technical difficulties occurred.
Format	Numeric (integer)
Values & definitions	Cumulative total of total circulatory arrest, in minutes, for the whole operation. Selective cerebral perfusion should not be considered as part of the circulatory arrest time.
Validation	Exact match according to perfusion record.
Other	

3.13 Catheter procedure duration

Description	The operative time taken.
Reason	Can be used as a risk factor and to identify procedures where technical difficulties occurred.
Format	Numeric (integer)
Values & definitions	Defined as first needle to skin to final catheter withdrawal, in minutes. This does not include the time taken for induction of anaesthesia, or local pressure for haemostasis after catheter withdrawn. If the patient is on ECLS then the catheter time out isn't relevant; use the time out of theatre.
Validation	Within 10% in minutes.
Other	

3.14 Total fluoroscopy time

Description	The total time fluoroscopy was used during the procedure
Reason	Can be used as a risk factor and to identify procedures where technical difficulties occurred.
Format	Numeric (integer)
Values & definitions	Cumulative fluoroscopy time in minutes for this procedure
Validation	Within 10% in minutes
Other	

3.15 Total fluoroscopy dose

Description	The total fluoroscopy dose during the procedure
Reason	Can be used as a risk factor and to identify procedures where technical difficulties occurred.
Format	Numeric (integer)
Values & definitions	Total dose in cGy/cm^2
Validation	Within 10% in cGy/cm^2
Other	

3.16 Procedure report or comment

Description	Accompanying text that can help describe the procedure in cases where coding is thought to be inadequate.
Reason	Can aid data validation
Format	Text (single value)
Values & definitions	Optional free text. Be very brief, only fill in if you feel a brief explanatory note is required for NCHDA (e.g. for "other procedures not listed"), or explaining extraordinary circumstances that may have led to a listed complication.
Validation	Not validated
Other	Do not include any patient identifiers in this section

4.01 Date of Discharge

Description	The date the patient is discharged from your hospital.
Reason	Length of stay is a risk factor and can also be used to quantify resource usage.
Format	Date (dd/mm/yyyy)
Values & definitions	The start of a period of home leave should not be counted as the date of discharge.
Validation	Exact match
Other	Valid date >1957 and <=Today

4.02 Date of Death

Description	The documented date of death.
Reason	Date of death is one of the principal outcomes of congenital heart disease care and intervention. Required for epidemiological analysis and assessment of health services delivery.
Format	Date (dd/mm/yyyy)
Values & definitions	The date of death as recorded on the death certificate or documented in the clinical notes. This may be after the date of discharge and should be updated when known to aid with longer term outcome assessment, i.e. can and should be submitted independent of a linked procedure when this occurs after hospital discharge.
Validation	Exact match
Other	Valid date >1957 and <=Today Used for ascertaining deaths within 30-days of a procedure and thereafter. Used for tabulated outcome data on the NICOR website, the funnel plots and for PRAiS.

4.03 Discharge status

Description	The status of the patient at discharge from your hospital.
Reason	Identified as one of the principal outcomes of congenital heart disease care and intervention.
Format	Text (single value)
Values & definitions	A. Alive D. Died in hospital 9. Unknown
Validation	Exact match
Other	

4.04 Discharge destination

Description

The immediate destination following discharge from your hospital

Reason

Required for epidemiological analysis and assessment of health services delivery.

Format

Text (single value)

Values & definitions

1. Home
2. Other hospital
3. Convalescence
4. Death
5. Death with referral to coroner
6. Hospice/palliative care
8. Other specialty in same hospital
9. Unknown

Validation

Exact match

Other

Option 5 and 6 only valid for data submitted for procedures from April 1st 2017.

If patient is discharged home for palliative care option '6. Hospice/palliative care' should be selected instead of option '1. Home'

4.05 Postprocedure seizures

Description	Any postprocedural convulsions/seizures requiring medication
Reason	An important outcome measure and can be a risk indicator for subsequent procedures.
Format	Text (single value)
Values & definitions	1. Yes 2. No
Validation	Exact match
Other	Post-procedure seizures requiring any kind of medication. If the patient is on medication(s) for seizures you should enter 'Yes' irrespective of whether they are currently having seizures or not. Seizure activity that resolves without medication should be reported as 'No'.

4.07 Duration of postoperative intubation

Description

Duration of postoperative intubation associated with a procedure.

Reason

Long term need for post-operative intubation is an important outcome measure.

Format

Numeric (integer)

Values & definitions

Total, cumulative number of days of postoperative endotracheal intubation.

A day is defined as any period between 00:01 and 24:00, even if that is just a matter of minutes.

It is possible, therefore to have a value of 2 days for this field despite being ventilated for a matter of minutes (the purpose of this field is to identify long term postoperative ventilation).

Day 1 is the day of operation, as is the case for PICANet.

It includes any days of invasive ventilation during the PICU stay associated with the procedure. For non-tracheostomy patients this does not include non-invasive CPAP or optiflow.

For patients with a permanent tracheostomy only count the days when the patient is having respiratory support – mechanical ventilation or CPAP.

Validation

Exact match

Other

4.08 Postoperative complications

Description

Significant postoperative complications within 30 days following surgery.

Reason

The presence of significant postoperative complications is an important outcome measure.

Format

Text (multivalue ; separated)

Values & definitions

159003. No postprocedural complications
Selecting this option PRECLUDES the selection of any other options

110633. Procedure related complete atrioventricular block requiring permanent pacemaker system

124307. Unplanned reoperation/ reintervention within 30 days of procedure (excludes bleeding)

150002. Cardiac arrest following procedure

150009. Requirement for mechanical circulatory support

156741. Surgical site infection requiring surgical intervention

158064. Prolonged pleural drainage > 7 days (code is retired and not used from 01.04.23)

158065. Postprocedural prolonged pleural drainage (over 10 days)

158086. Postprocedural requirement for tracheostomy

158190. Phrenic nerve injury requiring plication of diaphragm

158213. Acute kidney injury requiring dialysis

158257. New neurological impairment (global or focal) present at discharge

158375. Postprocedural necrotising enterocolitis - established requiring treatment

158399. Acute neurological event during or within 30 days after cardiovascular procedure

159014. Procedure related complication

159014 to be used if there is a significant complication not included in the list. Additional text can be entered in the procedure comment field to clarify.

"A complication is an event or occurrence that is associated with a disease or a healthcare intervention, is a departure from the desired course of events, and may cause, or be associated with, suboptimal outcome. A complication does not necessarily represent a breech in the standard of care that constitutes medical negligence or medical malpractice. An operative or procedural complication is any complication, regardless of cause, occurring (1) within 30 days after surgery or intervention in or out of the hospital, or [(2) after 30 days during the same hospitalization subsequent to the operation or intervention][1]. Operative and procedural complications include both intraoperative/intraprocedural complications and postoperative/postprocedural complications in this time interval."

'Introduction – Databases and the assessment of complications associated with the treatment of patients with congenital cardiac disease'

Cardiology in the Young 2008; 18(Suppl. 2): 1–37, Cambridge University Press: ISSN 1047-9511, doi:10.1017/S104795110800334X

For more detailed definitions see 'Complication definitions'

Format expected:

159003. No postprocedural complications

Validation

Exact match

Other

Used in the Specialised Services Quality Dashboards (SSQ dashboard) with the exception of '159014. Procedure related complication' and '159003. No postprocedural complications'

[1] Not used in NCHDA dataset

4.09 Attribution of death

Description	The attribution of death to a procedure
Reason	To identify any association between a procedure and death
Format	Text (single value)
Values & definitions	This is only to be completed if 4.03 Discharge status is 'D. Died in hospital' Otherwise to be blank. 123331. Intraoperative death 123334. Death unrelated to cardiac procedure 158264. Postprocedural brain death 159085. Death attributable to complications following premature birth 159086. Death attributable to complication(s) following congenital cardiac procedure
Validation	Exact match
Other	

5.01 Device manufacturer

Description	The manufacturer of any implanted devices.
Reason	For tracking of devices that might be involved in a product recall. For audits of device usage and outcomes.
Format	Free text (this is a ; separated list if multiple devices used)
Values & definitions	Manufacturer of any implanted device, valve or valved conduit, whether active (e.g. pacemaker) or passive (e.g. ductal occluder). Only devices **permanently** left in the patient should be recorded. This **excludes** patches, valveless conduits, shunts, homografts, temporary pacing leads, balloons etc. If a device is inserted in the body but has to be retrieved during same procedure due to embolization or failure to be deployed correctly, the details of this device are not required, however, the procedure performed must be coded as failed intervention.
Validation	Exact match
Other	

5.02 Device model

Description	The model numbers of any implanted device.
Reason	For tracking of devices that might be involved in a product recall. For audits of device usage and outcomes.
Format	Free text (this is a ; separated list if multiple devices used)
Values & definitions	Model name and/or number of any implanted device, valve or conduit, whether active (e.g. pacemaker) or passive (e.g. ductal occluder). Only devices **permanently** left in the patient should be recorded. This **excludes** patches, valveless conduits, shunts, homografts, temporary pacing leads, balloons etc. If a device is inserted in the body but has to be retrieved during same procedure due to embolization or failure to be deployed correctly, the details of this device are not required, however, the procedure performed must be coded as failed intervention.
Validation	Exact match
Other	

5.03 Device serial number

Description

The serial numbers of any devices implanted.

Reason

For tracking of devices that might be involved in a product recall.
For audits of device usage and outcomes.

Format

Free text (this is a ; separated list if multiple devices used)

Values & definitions

Serial number or batch number of any implanted device, valve or valved conduit, whether active (e.g. pacemaker) or passive (e.g. ductal occluder). Only devices **permanently** left in the patient should be recorded.

This **excludes** patches, valveless conduits, shunts, homografts, temporary pacing leads, balloons etc. If a device is inserted in the body but has to be retrieved during same procedure due to embolization or failure to be deployed correctly, the details of this device are not required, however, the procedure performed must be coded as failed intervention.

Some coils and other implantable devices do not have a serial number but do have a lot number or batch number you should submit this for those devices e.g. coils.

Validation

Exact match

Other

5.04 Device size

Description	The size of any devices implanted.
Reason	For tracking of devices that might be involved in a product recall. For audits of device usage and outcomes.
Format	Free text
Values & definitions	Device size diameter (mm) where relevant (e.g. for valve, valved conduit, closure device, coil or stent). To uniquely identify devices and stents the diameter and length should be entered. Only devices **permanently** left in the patient should be recorded. For stents the unexpanded size should be entered.
Validation	Exact match
Other	

6.01 Preprocedure NYHA status

Description The patient's preprocedural NYHA status.

Reason Preprocedural NYHA status is a risk factor.
A change in NHYA status is an important outcome measure.

Format Text (single value)

Values & definitions

1. No limitation of physical activity: Preprocedure dyspnoea status within 2 weeks of procedure. Patients with cardiac disease but without limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation or dyspnoea. Asymptomatic patients should be classified as Class 1.

2. Slight limitation of ordinary physical activity: Cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitations or dyspnoea.

3. Marked limitation of ordinary physical activity: Cardiac disease resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary physical activity results in fatigue, palpitations or dyspnoea.

4. Symptoms at rest or minimal activity: Cardiac disease resulting in an inability to conduct any physical activity without discomfort. Symptoms of cardiac failure may be present even at rest. If any physical activity is undertaken discomfort is increased.

Values expected:

1. No limitation of physical activity
2. Slight limitation of ordinary physical activity
3. Marked limitation of ordinary physical activity
4. Symptoms at rest or minimal activity

Validation Exact match

Other ACHD only (16 years of age and older (>=16.00 years of age))

6.02 Preprocedure smoking or vaping status

Description The patient's preprocedural smoking/vaping status

Reason The preprocedural history of cigarette use is a risk factor.

Format Text (single value)

Values & definitions Cigarette consumption and/or vaping is included.

0. Never smoked or vaped: NB: Patient has never smoked cigarettes or vaped
1. Ex smoker or vape user: Patient has not smoked cigarettes or vaped in the last month.
2. Current smoker: Patient regularly smokes one or more cigarette per day or has smoked in the last month.
3. Vaping: Patient regularly vapes at least once a day or has vaped in the last month.
9. Smoking or vaping status unknown

Values expected:

0. Never smoked or vaped
1. Ex smoker or vape user
2. Current smoker
3. Vaping
9. Smoking or vaping status unknown

Validation Exact match

Other ACHD only (16 years of age and older (>=16.00 years of age))

6.03 Preprocedure diabetes

Description The patient's preprocedural diabetes status

Reason The preprocedural presence of diabetes is a risk factor.

Format Text (single value)

Values & definitions

0. Not diabetic: Patient does not have diabetes.
1. Diet: The patient has received dietary advice appropriate to their condition but is not receiving medication.
2. Oral therapy: The patient uses oral medication to control their condition.
3. Insulin: The patient uses insulin treatment, with or without oral therapy, to control their condition.
9. Diabetes status unknown

Values expected:

0. Not diabetic
1. Diet
2. Oral therapy
3. Insulin
9. Diabetes status unknown

Validation Exact match

Other ACHD only (16 years of age and older (>=16.00 years of age))

6.04 History of pulmonary disease

Description The patient's preprocedural pulmonary disease status

Reason The preprocedural presence of pulmonary disease is a risk factor.

Format Text (single value)

Values & definitions

0. No pulmonary disease: No medication required
1. COAD/emphysema, asthma, AVM or other: Patient requires medication (inhalers, aminophylline or steroids) for chronic pulmonary disease or FEV1 less than 75% predicted value as taken from actual lung function tests. Venous pO_2 < 60 mmHg, pCO_2 > 50 mmHg. Asthma. Intermittent or allergic reversible airways disease treated with bronchodilators or steroids. Also select this option for significant pulmonary AV malformation, such as pulmonary arteriovenous fistula.
9. Unknown.

Values expected:

0. No pulmonary disease
1. COAD/emphysema, asthma, AVM or other
9. Unknown

Validation Exact match

Other ACHD only (16 years of age and older (>=16.00 years of age))

6.06 Preprocedural ischaemic heart disease

Description The patient's preprocedural ischaemic heart disease status

Reason The preprocedural presence of ischaemic heart is a risk factor.

Format Text (single value)

Values & definitions

0. No history of ischaemic heart disease:
1. History of Ischaemic heart disease: Ischaemic heart disease demonstrated by previous MI, abnormal coronary angiogram, previous PCI or CABG
9. Unknown

Values expected:

0. No history of ischaemic heart disease
1. History of Ischaemic heart disease
9. Unknown

Validation Exact match

Other ACHD only (16 years of age and older (>=16.00 years of age))

7.01 Preprocedural valve or septal defect or vessel size

Description	The preprocedural size of the valve or septal defect or vessel size
Reason	Useful for auditing outcomes of specific groups: for example large secundum ASD.
Format	Numeric (integer)
Values & definitions	Preprocedural valve or septal defect or vessel size (mm) If multiple defects are ballooned for example then the smallest value should be recorded. If multiple defects are closed then the largest value should be recorded. For PDA size please provide the smallest measurement.
Validation	Exact match: there may be some difficulty validating the single value submitted in complex procedures where a combination of device closures and ballooning may occur.
Other	

7.02 Sizing balloon used for septal defect closure Y/N

Description Was a sizing balloon used for septal defect occlusion

Reason For audit of current practice

Format Text (single value)

Values & definitions

1. Yes
2. No

Validation Exact match

Other

7.03 Number of stents or coils

Description	The number of stents and/or coils deployed
Reason	For audit and assessing procedure complexity
Format	Numeric (integer)
Values & definitions	The total count of the number of stents and coils deployed during the procedure. No other device types should be included. Any devices deployed that are removed for technical reason should not be included.
Validation	Exact match
Other	

7.04 Catheterisation complication severity rating

Description Classifies the severity of the most major catheter complication.

Reason Identified as one of the principal outcomes of congenital heart disease care and intervention.

Format Text (single value)

Values & definitions

Q10980. No adverse effect: No harm, no change in condition, may have required monitoring to assess for potential change in condition with no intervention indicated

Q10981. Mild: Transient change in condition, not life-threatening, condition returns to baseline, required monitoring, required minor intervention such as holding a medication (withholding a medication or, in other words, not administering a medication that was scheduled or planned to be given), or obtaining laboratory test(s)

Q10982. Moderate: Transient change in condition may be life-threatening if not treated, condition returns to baseline, required monitoring, required intervention such as reversal agent, additional medication, transfer to intensive care unit for monitoring, or moderate transcatheter intervention to correct condition

Q10983. Major: Change in condition, life-threatening if not treated, change in condition may be permanent, may have required intensive care unit admission or urgent readmission to hospital may have required invasive monitoring, required interventions such as electrical cardioversion or unanticipated intubation or required major invasive procedures or transcatheter interventions to correct condition.

Q10984. Catastrophic: Any complication associated with subsequent death.

If multiple catheter complications are present then score the most severe.

Values expected:

Q10980. No adverse affect
Q10981. Mild
Q10982. Moderate
Q10983. Major
Q10984. Catastrophic

Validation Exact match

Other

7.05 Catheterisation complications

Description

Significant postprocedural complications within 30 days following a cardiac catheter

Reason

Identified as one of the principal outcomes of congenital heart disease care and intervention.

Format

Text (multiple values)

Values & definitions

159003. No postprocedural complications**:**
Selecting this option PRECLUDES the selection of any other options

124307. Unplanned reoperation/ reintervention within 30 days of procedure (excludes bleeding)

150002. Cardiac arrest following procedure

155037. Embolisation of catheter introduced device

155040. Failed attempt to implant coil-device during transcatheter intervention

155052. Erosion of or into cardiac structure by implanted transcatheter device

155061. Coronary arterial compression following transluminal device implantation

155065. Embolisation (dislodgement) of catheter introduced coil

155071. Embolisation of stent

155078. Rupture of conduit or vessel following stent implantation

155091. Stent left expanded in unplanned site after migration or embolisation

155151. Local complication at access site of cardiac catheterisation requiring transfusion

155152. Local complication at access site of cardiac catheterisation requiring thrombolysis

155153. Local complication at access site of cardiac catheterisation requiring surgical intervention

155154. Mechanical haemolysis due to transcatheter implanted device or coil requiring transfusion

158257. New neurological impairment (global or focal) present at discharge

158375. Postprocedural necrotising enterocolitis - established requiring treatment

158399. Acute neurological event during or within 30 days after cardiovascular procedure

159094. Requirement for bail out transcatheter procedure following procedural complication

'This complication should be used for any emergency transcatheter procedure during the same admission as the planned catheter. The procedure should be cardiothoracic (rather than for peripheral vascular complications at access sites) and be prompted and indicated by a need to correct as an emergency a complication of the catheter such as cardiac or vessel perforation, device embolisation, etc.'

159095. Requirement for bail out surgical procedure following procedural complication

Complication should be coded as '159003. No postprocedural complications' in the following 2 situations: 1) intention to carry out catheter intervention which does not happen for some reason, such as inability to get a guide wire across the defect. Device/stent is NOT introduced into the patient. 2) A device/stent is introduced into the patient, deployed and removed or device/stent is introduced but is unstable and removed.

However, if a device/stent is introduced into the patient and is deployed but then migrates/embolises and is either parked elsewhere in vasculature or retrieved, '155040. Failed attempt to implant coil-device during transcatheter intervention' should be used alongside any other catheter complication codes relevant to the situation.

'This complication should be used for any emergency cardiothoracic surgical procedure during the same admission as the catheter. The surgery should be cardiothoracic (rather than for peripheral vascular complications at access sites) and be prompted and indicated by a need to correct as an emergency a complication of the planned catheter procedure, such as cardiac or vessel perforation, dissection of a thoracic great vessel, device embolisation, etc.'

155000. Cardiac catheterisation complication
Only use if none of the above are applicable, text can be added to the procedure comment to clarify/specify

"A complication is an event or occurrence that is associated with a disease or a healthcare intervention, is a departure from the desired course of events, and may cause, or be associated with, suboptimal outcome. A complication does not necessarily represent a breech in the standard of care that constitutes medical negligence or medical malpractice. An operative or procedural complication is any complication, regardless of cause, occurring (1) within 30 days after surgery or intervention in or out of the hospital, [or (2) after 30 days during the same hospitalization][2] subsequent to the operation or intervention. Operative and procedural complications include both intraoperative/intraprocedural complications and postoperative/postprocedural complications in this time interval."

'Introduction – Databases and the assessment of complications associated with the treatment of patients with congenital cardiac disease'

Cardiology in the Young 2008; 18(Suppl. 2): 1–37, Cambridge University Press: ISSN 1047-9511, doi:10.1017/S104795110800334X

For more detailed definitions see 'Complication definitions'

Format expected:

159003. No postprocedural complications

Validation

Exact match

Other

Used in the Specialised Services Quality Dashboards (SSQ dashboard) with the exception of '155000. Cardiac catheterisation complication' and '159003. No postprocedural complications

[2] Not used in NCHDA dataset

8.01 Unique Procedure identifier

Description	This is a system generated unique identifier for a procedure.
Reason	To help prevent duplication when the record key values are changed.
Format	Text (single value)
Values & definitions	A host system generated unique string to identify this procedure. Is used to identify the same record when re-importing/updating data. This should prevent the creation of duplicates that can happen when part of the record key is changed between data uploads.
Validation	Not validated
Other	**In the absence of the unique procedure identifier:** The following combination of variables are used to determine if a record(s) already exist in the NCHDA database, if any part of this key has changed for a particular record in your source database, it may result in a duplicate record being created. Patient Key = Hospital identifier (1) + HospitalNumber (2) Procedure Key = Hospital identifier (1) + HospitalNumber (2) + ProcedureDate (17) + PrimaryProcedure (25)

File import specification

To upload a file into NICOR Congenital, it must contain the following 63 fields in this order and fields must be comma separated **and** enclosed in quotes (not smart quotes). Records must be separated by a line break (CR/LF)

Note: Optional additional field 62 at 8.01, Unique Procedure ID – this can be a blank field but must be supplied in the file.

Field order

1.00	Dataset version
1.01	Hospital identifier
1.02	Patient Case Record Number
1.03	NHS Number
1.04	Patient Surname
1.05	Patient Forename
1.06	Patient Date of Birth
1.07	Patient Gender
1.08	Patient Ethnic Group
1.09	Patient Admin status
1.10	Patient Post Code
2.01	Diagnosis
2.02	Previous procedure
2.03	Weight
2.03b	Height
2.04	Antenatal Diagnosis
2.05	Preprocedure seizures
2.06b	Comorbidity present
2.07	Comorbid conditions
2.08	Preprocedure systemic ventricular ejection fraction
2.09	Preprocedure subpulmonary ventricular ejection fraction
3.01	Date/Time procedure
3.01b	Procedure urgency
3.01c	Unplanned reoperation
3.02	Consultant Responsible for Procedure
3.02c	Single operator procedure
3.03	First operator
3.04	First operator grade
3.05	First assistant
3.06	First assistant grade
3.07	Type of Procedure
3.08	Sternotomy sequence
3.09	Operation performed
3.10	Total bypass time
3.11	Total bypass cross clamp time
3.12	Total circulatory arrest time
3.13	Catheter procedure duration
3.14	Total fluoroscopy time
3.15	Total fluoroscopy dose
3.16	Procedure report or comment
4.01	Date of Discharge
4.02	Date of Death
4.03	Discharge status
4.04	Discharge destination

4.05	Postprocedure seizures
4.07	Duration of postoperative intubation
4.08	Postoperative complications
5.01	Device manufacturer
5.02	Device model
5.03	Device serial number
5.04	Device size
6.01	Preprocedure NYHA status
6.02	Preprocedure smoking status
6.03	Preprocedure diabetes
6.04	History of pulmonary disease
6.06	Preprocedural ischaemic heart disease
7.01	Preprocedural valve or septal defect or vessel size
7.02	Sizing balloon used for septal defect closure Y/N
7.03	Number of stents or coils
7.04	Catheterisation complication severity rating
7.05	Catheterisation complications
8.01	Unique Procedure ID
4.09	Attribution of death

In the absence of the unique procedure identifier:
The following combination of variables are used to determine if a record(s) already exist in the NCHDA database, if any part of this key has changed for a particular record in your source database, it may result in a duplicate record being created.

Patient Key = Hospital identifier (1) + HospitalNumber (2)

Procedure Key = Hospital identifier (1) + HospitalNumber (2) + ProcedureDate (17) + PrimaryProcedure (25)

Long – Short code

Data can be submitted using a long or short code:
The long code method concatenates the code with the description and uses a ; to delimit values:

155052. Erosion of or into cardiac structure by implanted transcatheter device; 155071. Embolisation of stent

The short code has just the code delimited by ;
155052; 155071

The long version is the preferred option as it makes it easier to check both the data being uploaded and also for NICOR to check what they have received and identify any problems with the data format or content.

For data submitted to Qreg5 it is highly recommended to submit diagnosis, comorbidity, previous procedure and procedure using the short version because of potential mismatch with the term value in Qreg5.

Minor and excluded procedures (ignored by the specific procedures algorithm and activity algorithm)

This is the excluded list for v6.nn of the specific procedure algorithm and v6.nn of the activity algorithm. Please note this needs to be used in conjunction with the code lists supplied with the algorithms to ascertain the complete inclusion/exclusion list.

123200. Postoperative procedure
123206. Lung biopsy procedure
123214. DC cardioversion
123217. Parietal pleurectomy
123218. Postoperative procedure to control bleeding
123221. Cardiac procedure
123228. Thoracic duct occlusion
123229. Diaphragm procedure
123240. Pericardiocentesis
123241. Pericardial drainage: open (pericardiotomy)
123243. Pericardiocentesis: percutaneous transcatheter
123246. Pericardial window creation
123253. Pericardial biopsy
123259. Procedure involving pericardium
123270. Plication of hemidiaphragm
123280. Insertion of pleural tube drain
123283. Insertion of mediastinal tube drain
123290. Instigation of renal dialysis
123351. Peripheral vascular procedure
123352. Non-cardiothoracic-vascular procedure
123353. Non-cardiothoracic-vascular procedure on cardiac patient under cardiac anaesthesia
124000. Thoracotomy
124006. Video-assisted thoracoscopic approach (VATS)
124013. Minimally invasive procedure
124029. Median sternotomy: redo x 1-3
124030. Median sternotomy: redo x 4 or more
124099. Cardiac incision
124300. Reoperation
124325. Palliative procedure
126400. Bronchoscopy
126408. Bronchoscopic removal of foreign body
126420. Tracheal procedure
126421. Tracheostomy creation
126440. Tracheobronchial reconstruction procedure
126505. Mediastinal exploration
126506. Mediastinal procedure
126513. Pectus carinatum repair

126514. Pectus excavatum repair
126523. Anterior chest wall (pectus) repair
126545. Debridement of chest wall incision
126548. Sternal wire removal from previous sternotomy
126556. Sternotomy wound drainage
126560. Delayed closure of sternum
126572. Open excision of pleural lesion
126582. Pleurodesis
126589. Pleural procedure
126600. Lung procedure
126601. Lung decortication
126602. Lung mass excision
126605. Lung lobectomy
126606. Pneumonectomy
126607. Lung sequestration repair
128000. Thoracic-mediastinal procedure
128701. Cardiac support procedure
128728. Procedure involving Extracorporeal Membrane Oxygenation (ECMO) circuitry
128736. Mechanical life support procedure for primary respiratory failure
128737. Mechanical life support procedure following cardiac procedure
128745. Take down (decannulation) of Extracorporeal Membrane Oxygenation (ECMO) circuitry
128753. Mechanical life support procedure as destination therapy
130014. Insertable electrocardiogram (ECG) loop recorder (e.g. Reveal) implantation
130015. Insertable electrocardiogram (ECG) loop recorder (e.g. Reveal) removal
130100. Echocardiographic examination
130102. Transthoracic echocardiographic examination
130103. Transoesophageal echocardiographic examination
130104. Epicardial echocardiographic examination

There are a number of procedures that were in the list that have now been incorporated into procedural counts. These procedures are ignored by the specific procedure and activity analysis algorithms.

PRAiS2 minor and excluded list.
Note: PRAiS2 uses the v5.05 dataset list – dated 25/05/2016.

120625. Transluminal RV biopsy
122341. Transluminal intracoronary echocardiography (IVUS)
123200. Postoperative procedure
123206. Lung biopsy procedure
123214. DC cardioversion
123217. Parietal pleurectomy
123218. Postoperative procedure to control bleeding
123221. Cardiac procedure (DESCRIBE)
123228. Thoracic duct occlusion

123229. Diaphragm procedure
123240. Pericardiocentesis
123241. Pericardiocentesis - open
123243. Pericardiocentesis - transcatheter
123246. Pericardial window creation
123253. Pericardial biopsy
123259. Procedure involving pericardium (DESCRIBE)
123270. Plication of hemidiaphragm
123280. Insertion of pleural tube drain
123283. Insertion of mediastinal tube drain
123310. Traumatic injury of heart repair
123351. Peripheral vascular procedure (DESCRIBE)
123352. Non-cardiothoracic / vascular procedure (DESCRIBE)
123353. Non-cardiothoracic-vascular procedure on cardiac patient under cardiac anaesthesia
123514. Removal of complete implanted cardiac pacemaker system
123713. Single lung transplant
123720. Double lung transplant
123760. Lung(s) transplant
124000. Thoracotomy
124006. Thoracoscopic approach (VATS)
124013. Minimally invasive procedure
124099. Cardiac incision
124300. Reoperation
124325. Palliative procedure
124500. Transluminal catheter procedure
124504. Transluminal retrieval of device/ foreign body
124507. Transluminal diagnostic test occlusion
124559. Transluminal procedure using adjunctive therapy
126400. Bronchoscopy
126408. Bronchoscopic removal of foreign body
126420. Tracheal procedure (DESCRIBE)
126421. Tracheostomy creation
126440. Tracheobronchial reconstruction procedure
126505. Mediastinal exploration
126506. Mediastinal procedure
126513. Pectus carinatum repair
126514. Pectus excavatum repair
126523. Anterior chest wall (pectus) repair
126545. Debridement of chest wall incision
126548. Sternal wire removal from previous sternotomy
126556. Sternotomy wound drainage
126560. Delayed closure of sternum
126572. Open excision of pleural lesion
126582. Pleurodesis
126589. Pleural procedure (DESCRIBE)
126600. Lung procedure
126601. Lung decortication

126602. Lung mass excision
126605. Lung lobectomy
126606. Pneumonectomy
126607. Lung sequestration repair
128000. Thoracic / mediastinal procedure (DESCRIBE)
128701. Cardiac support procedure
128722. RV assist device implantation
128723. LV assist device implantation
128724. Biventricular assist device implantation
128725. Cardiac support using ECMO circuitry
128728. Procedure involving Extracorporeal Membrane Oxygenation (ECMO) circuitry
130014. Insertable electrocardiogram (ECG) loop recorder (e.g. Reveal) implantation
130015. Insertable electrocardiogram (ECG) loop recorder (e.g. Reveal) removal
130100. Echocardiographic examination
130102. Transthoracic echocardiographic examination
130103. Transoesophageal echocardiography
130104. Epicardial echocardiographic examination
130124. Transluminal intracardiac echocardiographic examination
130127. Intravascular ultrasound (IVUS) examination
130501. Diagnostic catheterisation procedure
130505. Diagnostic cardiovascular catheterisation procedure: angiographic data obtained
130506. Diagnostic cardiovascular catheterisation procedure: haemodynamic data obtained
130507. Diagnostic cardiovascular catheterisation procedure with haemodynamic alteration (challenge)
130508. Diagnostic cardiovascular catheterisation procedure with electrophysiological alteration (challenge)

Pseudo postcodes

These postcodes should be used for foreign nationals or individuals where residence cannot be established

NB: these codes are not allocated by the Royal Mail, they are allocated by the Organisational Codes Service (OCS) of the NHSIA (see references below)

http://www.nhsia.nhs.uk/datastandards/pages/ddm12/textaa/textaa_postcode.htm
http://www.nhsia.nhs.uk/datastandards/pages/ddm12/dinote/dinote_POSTCODEOFUSUALADDRESS.htm

Postcode	Country
ZZ99 9FZ	Abu Dhabi
ZZ99 9FZ	Aden
ZZ99 9GZ	Afghanistan
ZZ99 9FZ	Ajman
ZZ99 4UZ	Albania
ZZ99 3HZ	Alderney
ZZ99 8KZ	Algeria
ZZ99 9UZ	American (East) Samoa
ZZ99 2HZ	Andorra – new from 1998
ZZ99 4HZ	Andorra (with Spain) – closed 1997
ZZ99 8EZ	Angola
ZZ99 6RZ	Anguilla
ZZ99 6RZ	Antigua
ZZ99 6RZ	Antigua & Barbuda
ZZ99 7FZ	Argentina
ZZ99 7FZ	Argentina Antarctic Territory
ZZ99 7JZ	Armenia
ZZ99 7CZ	Aruba
ZZ99 6UZ	Ascension Island
ZZ99 6GZ	Australia
ZZ99 6GZ	Australian Antarctic Territory
ZZ99 4MZ	Austria
ZZ99 7KZ	Azerbaijan
ZZ99 4JZ	Azores
ZZ99 6RZ	Bahamas
ZZ99 9FZ	Bahrain
ZZ99 9HZ	Bali
ZZ99 6BZ	Bangladesh
ZZ99 8FZ	Bantu Homelands
ZZ99 6MZ	Barbados
ZZ99 6RZ	Barbuda
ZZ99 7MZ	Belarus
ZZ99 2DZ	Belgium – new from 1998
ZZ99 4DZ	Belgium (with Luxembourg) – closed 1997

ZZ99 6LZ	Belize
ZZ99 6BZ	Benin
ZZ99 6RZ	Bermuda
ZZ99 9GZ	Bhutan
ZZ99 7HZ	Bolivia
ZZ99 7CZ	Bonaire
ZZ99 8FZ	Bophuthatswana
ZZ99 5NZ	Bosnia and Herzegovina
ZZ99 5GZ	Botswana
ZZ99 7DZ	Brazil
ZZ99 6UZ	British Antarctic Territory
ZZ99 5RZ	British Indian Ocean Territory
ZZ99 6RZ	British Virgin Islands
ZZ99 6EZ	Brunei
ZZ99 4UZ	Bulgaria
ZZ99 8BZ	Burkina Faso
ZZ99 9GZ	Burma (Myanmar)
ZZ99 8CZ	Burundi
ZZ99 8EZ	Cabinda
ZZ99 9HZ	Cambodia
ZZ99 8CZ	Cameroon
ZZ99 6KZ	Canada
ZZ99 7BZ	Canal Zone
ZZ99 4HZ	Canary Islands
ZZ99 8AZ	Cape Verde
ZZ99 9MZ	Caroline Islands
ZZ99 6RZ	Cayman Islands
ZZ99 9HZ	Celebes (Sulawesi)
ZZ99 8CZ	Central African Republic
ZZ99 8WZ	Ceuta and Melilla
ZZ99 8AZ	Chad
ZZ99 3HZ	Channel Islands
ZZ99 7GZ	Chile
ZZ99 7GZ	Chilean Antarctic
ZZ99 9JZ	China (People's Republic of)
ZZ99 6JZ	Christmas Island
ZZ99 6JZ	Cocos (Keeling) Islands
ZZ99 7EZ	Colombia
ZZ99 9LZ	Commonwealth of (Russian) Independent States
ZZ99 8RZ	Comoros
ZZ99 8CZ	Congo
ZZ99 6JZ	Cook Islands
ZZ99 6JZ	Coral Sea Islands Territory
ZZ99 7BZ	Costa Rica
ZZ99 4RZ	Crete (Kriti)
ZZ99 5VZ	Croatia
ZZ99 7CZ	Cuba

ZZ99 7CZ	Curacao
ZZ99 6AZ	Cyprus
ZZ99 4SZ	Czechoslovakia – closed 1996
ZZ99 5XZ	Czech Republic
ZZ99 8CZ	Democratic Republic of Congo
ZZ99 4FZ	Denmark (not including Greenland)
ZZ99 8QZ	Djibouti
ZZ99 4RZ	Dodecanese Islands
ZZ99 6RZ	Dominica
ZZ99 7CZ	Dominican Republic
ZZ99 9FZ	Dubai
ZZ99 6UZ	East Falkland
ZZ99 4NZ	East Germany – closed 1996
ZZ99 7EZ	Ecuador
ZZ99 8MZ	Egypt
ZZ99 7BZ	El Salvador
ZZ99 3CZ	England
ZZ99 8CZ	Equatorial Guinea
ZZ99 8QZ	Eritrea
ZZ99 7LZ	Estonia
ZZ99 8QZ	Ethiopia
ZZ99 4WZ	Faeroe Islands
ZZ99 6UZ	Falkland Islands
ZZ99 6JZ	Fiji
ZZ99 4BZ	Finland
ZZ99 4GZ	France (not including Monaco)
ZZ99 7EZ	French Guinea
ZZ99 9MZ	French Polynesia
ZZ99 9MZ	French Southern and Antarctic Lands
ZZ99 9FZ	Fujairah
ZZ99 8CZ	Gabon
ZZ99 5CZ	Gambia, The
ZZ99 7NZ	Georgia
ZZ99 4QZ	Germany
ZZ99 5DZ	Ghana
ZZ99 5AZ	Gibraltar
ZZ99 6UZ	Gough Island
ZZ99 3CZ	Great Britain
ZZ99 4RZ	Greece
ZZ99 2FZ	Greenland – new from 1998
ZZ99 4FZ	Greenland (with Denmark) – closed 1997
ZZ99 6RZ	Grenada
ZZ99 7CZ	Guadeloupe
ZZ99 9MZ	Guam

ZZ99 7BZ	Guatemala
ZZ99 3EZ	Guernsey (and Herm)
ZZ99 8AZ	Guinea
ZZ99 8AZ	Guinea- Bissau
ZZ99 6TZ	Guyana
ZZ99 7CZ	Haiti
ZZ99 6GZ	Heard and McDonald Islands
ZZ99 3EZ	Herm
ZZ99 7BZ	Honduras
ZZ99 6FZ	Hong Kong
ZZ99 4XZ	Hungary
ZZ99 4HZ	Ibiza
ZZ99 4CZ	Iceland
ZZ99 6UZ	Inaccessible Island
ZZ99 6CZ	India
ZZ99 9HZ	Indonesia
ZZ99 4RZ	Ionian Islands
ZZ99 9EZ	Iran
ZZ99 9DZ	Iraq
ZZ99 3AZ	Irish Republic
ZZ99 9AZ	Israel
ZZ99 4LZ	Italy
ZZ99 8BZ	Ivory Coast (Cote d'Ivoire)
ZZ99 6PZ	Jamaica
ZZ99 9KZ	Japan
ZZ99 9HZ	Java
ZZ99 3FZ	Jersey
ZZ99 3EZ	Jethou Island
ZZ99 7AZ	Johnston Atoll/Island
ZZ99 9FZ	Jordan
ZZ99 7PZ	Kazakhstan
ZZ99 5JZ	Kenya
ZZ99 7AZ	Kingman Reef
ZZ99 6JZ	Kiribati
ZZ99 9JZ	Korea, Democratic People's Republic of
ZZ99 9JZ	Korea, Republic of
ZZ99 9FZ	Kuwait
ZZ99 7QZ	Kyrgyzstan
ZZ99 9HZ	Lao People's Democratic Republic
ZZ99 7RZ	Latvia
ZZ99 9FZ	Lebanon
ZZ99 5GZ	Lesotho
ZZ99 8BZ	Liberia
ZZ99 8TZ	Libyan Arab Jamahiriya

ZZ99 2PZ	Liechtenstein – new from 1998
ZZ99 4PZ	Liechtenstein (with Switzerland) – closed 1997
ZZ99 3EZ	Lihou
ZZ99 7SZ	Lithuania
ZZ99 2EZ	Luxembourg – new from 1998
ZZ99 4DZ	Luxembourg (with Belgium) – closed 1997
ZZ99 9JZ	Macau (Macao)
ZZ99 5QZ	Macedonia
ZZ99 4JZ	Maderia Islands
ZZ99 8RZ	Malagasy Republic
ZZ99 5KZ	Malawi
ZZ99 6EZ	Malaysia
ZZ99 5RZ	Maldives, The
ZZ99 8AZ	Mali
ZZ99 5BZ	Malta
ZZ99 3BZ	Man, Isle of
ZZ99 7AZ	Marianas, Northern
ZZ99 9MZ	Marshall Islands
ZZ99 7CZ	Martinique
ZZ99 8AZ	Mauritania
ZZ99 5RZ	Mauritius
ZZ99 8WZ	Melilla
ZZ99 7BZ	Mexico
ZZ99 9MZ	Micronesia, The Federated States of
ZZ99 6UZ	Middle Island
ZZ99 9TZ	Moldova
ZZ99 2GZ	Monaco – new from 1998
ZZ99 4GZ	Monaco (with France) – closed 1997
ZZ99 9JZ	Mongolia
ZZ99 5SZ	Montenegro
ZZ99 6RZ	Montserrat
ZZ99 8JZ	Morocco
ZZ99 8HZ	Mozambique
ZZ99 8GZ	Namibia
ZZ99 6JZ	Nauru
ZZ99 9GZ	Nepal
ZZ99 7CZ	Netherlands Antilles
ZZ99 4EZ	Netherlands, The
ZZ99 9MZ	New Caledonia
ZZ99 9MZ	New Hebrides
ZZ99 6HZ	New Zealand
ZZ99 7BZ	Nicaragua
ZZ99 8AZ	Niger
ZZ99 5FZ	Nigeria
ZZ99 6UZ	Nightingale Island
ZZ99 6JZ	Niue

ZZ99 6JZ	Norfolk Island
ZZ99 2WZ	Northern Ireland
ZZ99 2AZ	Norway – new from 1998
ZZ99 4AZ	Norway (with Antarctic Territory and Sweden) – closed 1997
ZZ99 2BZ	Norwegian Antarctic Territory – new from 1998
ZZ99 4AZ	Norwegian Antarctic Territory (with Norway and Sweden) - closed 1997
ZZ99 9FZ	Oman
ZZ99 9NZ	Pakistan
ZZ99 7AZ	Palau
ZZ99 9CZ	Palestine
ZZ99 7AZ	Palmyra Islands
ZZ99 7BZ	Panama
ZZ99 7BZ	Panama Canal Zone
ZZ99 6JZ	Papua New Guinea
ZZ99 7HZ	Paraguay
ZZ99 7EZ	Peru
ZZ99 2BZ	Peter Island – new from 1998
ZZ99 4AZ	Peter Island (with Norway and Sweden) – closed 1997
ZZ99 9HZ	Philippines, The
ZZ99 6JZ	Pitcairn Islands Group
ZZ99 4YZ	Poland
ZZ99 4JZ	Portugal
ZZ99 7CZ	Puerto Rico
ZZ99 9FZ	Qatar
ZZ99 4AZ	Queen Maud Island
ZZ99 9FZ	Ras al Khaimah
ZZ99 8RZ	Reunion
ZZ99 4ZZ	Romania
ZZ99 6HZ	Ross Dependency
ZZ99 7UZ	Russia
ZZ99 8CZ	Rwanda
ZZ99 6RZ	St Christopher
ZZ99 6UZ	St Helena and Dependencies
ZZ99 6RZ	St Lucia
ZZ99 9WZ	St Pierre at Miguelon
ZZ99 6RZ	St Vincent and the Grenadines
ZZ99 4LZ	San Marino
ZZ99 8CZ	Sao Tome and Principe
ZZ99 3HZ	Sark, Little and Great
ZZ99 9FZ	Saudi Arabia
ZZ99 1WZ	Scotland
ZZ99 8AZ	Senegal

ZZ99 5TZ	Serbia
ZZ99 5RZ	Seychelles
ZZ99 9FZ	Sharjah
ZZ99 5EZ	Sierra Leone
ZZ99 6EZ	Singapore
ZZ99 5YZ	Slovakia
ZZ99 5UZ	Slovenia
ZZ99 6JZ	Solomon Islands
ZZ99 8QZ	Somalia
ZZ99 8FZ	South Africa
ZZ99 4HZ	Spain
ZZ99 6DZ	Sri Lanka
ZZ99 6UZ	Stoltenhoff Island
ZZ99 8PZ	Sudan
ZZ99 7EZ	Suriname
ZZ99 5GZ	Swaziland
ZZ99 2CZ	Sweden – new from 1998
ZZ99 4AZ	Sweden (with Norway) – closed 1997
ZZ99 4PZ	Switzerland (not including Liechtenstein)
ZZ99 9BZ	Syrian Arab Republic
ZZ99 9JZ	Taiwan (Formosa)
ZZ99 7VZ	Tajikistan
ZZ99 5LZ	Tanzania
ZZ99 9HZ	Thailand
ZZ99 9JZ	Tibet
ZZ99 8BZ	Togo
ZZ99 6JZ	Tokelau Islands
ZZ99 6JZ	Tonga
ZZ99 8FZ	Transkei
ZZ99 6QZ	Trinidad and Tobago
ZZ99 6UZ	Tristan da Cunha
ZZ99 8LZ	Tunisia
ZZ99 4KZ	Turkey
ZZ99 7XZ	Turkmenistan
ZZ99 6RZ	Turks and Caicos Islands
ZZ99 6JZ	Tuvalu
ZZ99 5MZ	Uganda
ZZ99 7YZ	Ukraine
ZZ99 9FZ	Umm al Qaiwain
ZZ99 9LZ	Union of Soviet Socialist States – closed 1996
ZZ99 9FZ	United Arab Emirates
ZZ99 3CZ	United Kingdom
ZZ99 7AZ	United States of America
ZZ99 7HZ	Uruguay
ZZ99 7ZZ	Uzbekistan

ZZ99 6JZ	Vanuatu
ZZ99 4LZ	Vatican City State
ZZ99 8FZ	Venda
ZZ99 7EZ	Venezuela
ZZ99 9HZ	Vietnam
ZZ99 7CZ	Virgin Islands (USA)
ZZ99 9MZ	Wake Island
ZZ99 3GZ	Wales
ZZ99 9MZ	Wallis and Futuna Islands
ZZ99 8FZ	Walvis Bay
ZZ99 9AZ	West Bank
ZZ99 6JZ	Western Samoa
ZZ99 6UZ	West Falkland
ZZ99 4QZ	West Germany
ZZ99 9FZ	Yemen
ZZ99 4TZ	Yugoslavia – closed 1996
ZZ99 5PZ	Zambia
ZZ99 5HZ	Zimbabwe

Comorbidity codes

As defined for the NCHDA dataset – this does not align with the PRAiS2 set of comorbidity codes listed further on in the data manual.

102000. No preprocedure risk factors

Or: single/multiple values

030209. Lung anomaly
030214. Functionally congenital single lung
030305. Tracheobronchial anomaly
030603. Intestines malrotated
030703. Spleen absent (asplenia)
030704. Multiple spleens (polysplenia)
070111. Right ventricular dysfunction
070610. Left ventricular dysfunction
100665. Preprocedural endocarditis
101239. Failure to thrive
101320. Secondary pulmonary hypertension
101321. Pulmonary hypertension due to congenital systemic-to-pulmonary shunt
101363. Elevated lung resistance for biventricular repair (over 6 Wood units)
101364. Elevated lung resistance for heart transplant (over 4 Wood units)
101365. Elevated lung resistance for univentricular repair (over 2 Wood units)
101400. Secondary systemic hypertension
101500. Neonatal disorder
101505. Necrotising enterocolitis
101512. Meconium aspiration
101723. Shock
101848. Personal history of ischaemic heart disease
102002. Preprocedural shock
102003. Preprocedural arrhythmia
102005. Preprocedural acidosis
102006. Preprocedural coagulation disorder
102007. Preprocedural renal failure (creatinine over 1.5 times upper limit of normal for age)
102008. Preprocedural renal failure requiring dialysis
102009. Preprocedural septicaemia
102012. Preprocedural neurological impairment
102013. Preprocedural cerebral abnormality on imaging
102014. Preprocedural mechanical ventilatory support
102015. Preprocedural mechanical circulatory support
102016. Preprocedural pulmonary hypertension
102017. Preprocedural tracheostomy
102018. Preprocedural seizures
102019. Preprocedural risk factor
102031. Preprocedural shock at time of surgery (persistent)
102032. Preprocedural shock resolved by time of surgery
102033. Preprocedural cardiopulmonary resuscitation (less than 48 hours)
102034. Preprocedural myocardial dysfunction

102037. Preprocedural respiratory syncytial virus (RSV) infection
102038. Preprocedural necrotising enterocolitis: treated medically
102039. Preprocedural necrotising enterocolitis: treated surgically
102045. Preprocedural pulmonary hypertension (pulmonary pressure more than or equal to systemic pressure): echo data
102046. Preprocedural pulmonary hypertension (pulmonary pressure more than or equal to systemic pressure): catheter data
102202. Premature birth
102205. Premature birth 32-35 weeks
102206. Premature birth less than 32 weeks
102207. Weight less than 2.5 kg
110635. Preprocedural complete atrioventricular block
140101. Chromosomal anomaly
140102. Trisomy 21: Down's syndrome
140103. Trisomy 18: Edwards' syndrome
140104. Trisomy 13: Patau's syndrome
140105. 45XO: Turner's syndrome
140121. 22q11 microdeletion
140200. Syndrome-association potentially with cardiac involvement
140206. 22q11 microdeletion with full DiGeorge sequence (including immune dysfunction)
140210. Friedreich's ataxia
140217. Marfan syndrome
140219. Noonan syndrome
140221. Pompe's disease: glycogen storage disease type IIa
140228. Tuberous sclerosis
140230. Williams syndrome (infantile hypercalcaemia)
140232. Fetal rubella syndrome
140234. Duchenne's muscular dystrophy
140258. Muscular dystrophy
140262. Ehlers-Danlos syndrome
140266. Alagille syndrome: arteriohepatic dysplasia
140300. Noncardiac abnormality potentially with associated heart disease
140304. Non-cardiothoracic-vascular abnormality
140305. Psychomotor developmental delay
140306. Cystic fibrosis
140307. Congenital diaphragmatic hernia
140308. Tracheo-oesophageal fistula
140309. Gastro-oesophageal reflux disease (GORD)
140310. Omphalocoele
140311. Duodenal stenosis/atresia
140321. Sickle cell disease
140323. Renal abnormality
140328. Congenital coagulation disorder
140329. Thoracic-mediastinal abnormality
140333. Microcephaly
140340. Brain abscess
140342. Cerebrovascular accident (stroke)
140347. Choanal atresia

140349. Tracheobronchial malacia
140352. Hypothyroidism
140359. Obesity (Body Mass Index over 30)
140372. Anoxic-ischaemic encephalopathy
140375. Hyperthyroidism
140390. Diabetes mellitus
140391. Cerebral anomaly
140392. Connective tissue disease
140412. Cleft lip or palate
140470. Smoking: tobacco use
140485. Loeys-Dietz Syndrome (transforming growth factor beta receptor (TGFBR) gene mutation)
140490. Von Willebrand disease
140494. Diabetes mellitus: requiring insulin
140495. Diabetes mellitus: on oral therapy
140496. Diabetes mellitus: mamaged with diet alone
140500. Maternal teratogen or disease potentially associated with congenital heart disease
140501. Maternal teratogen associated with congenital heart disease
140540. Maternally derived fetal disease or syndrome potentially with associated heart disease
140550. Major anomaly of gastrointestinal system
140565. Meningitis
140601. Multiple congenital malformations
141034. Intrauterine growth restriction (retardation)
158210. Kidney failure
160302. Lower respiratory tract infection
160305. Lung disease
160800. Acquired bronchial disease
160900. Airway disease
161320. Diaphragm paralysis
163001. Respiratory failure

PRAiS2 risk factors and definitions

The STS document with definitions can be downloaded from: http://www.sts.org/sites/default/files/documents/CongenitalDataSpecsV3_3_Updated.pdf

Additional patient risk factor	Definition of risk factor	Time line criteria for relating the risk factor to paediatric cardiac surgery	The most prevalent EPCC codes within each risk factor group
Congenital comorbidity, excluding Down's syndrome	A patient condition present at birth that is additional and separate to the congenital heart abnormality. This includes individual single abnormalities and recognised constellations of abnormality referred to as 'syndromes'.	Although present at birth these conditions are not always diagnosed immediately. This risk factor applies at any cardiac surgery performed throughout the child's life.	14.01.01. Chromosomal anomaly 14.02.00 Syndrome-association potentially with cardiac involvement 14.01.21. 22q11 microdeletion
Acquired comorbidity	An acquired condition that arises during life, which may be either temporary or permanent. This includes conditions incorporating secondary organ damage caused by congenital heart disease and rarely other acquired conditions that are unrelated to congenital heart disease.	This risk factor applies when the condition is diagnosed during the admission to hospital that immediately precedes the cardiac surgery.	14.03.05 Psychomotor developmental delay 10.15.05 Necrotising enterocolitis 10.20.09. Preprocedural septicaemia
Severity of illness indicator	These are events, supports or conditions, which indicate that the patient became severely unwell usually where the causation related to congenital heart disease.	For cardiac arrest and extracorporeal life support: these apply when present in the child during the admission to hospital that immediately precedes the cardiac surgery. For mechanical ventilation, metabolic acidosis and shock: these apply when present as the child enters the operating room for cardiac surgery.	10.20.14 Preprocedural mechanical ventilator support 10.20.02 Preprocedural shock 10.20.05 Preprocedural acidosis
Additional cardiac risk factors	These are conditions related to the heart, which may arise in conjunction with a congenital heart defect and have the potential to make a child undergoing cardiac surgery more complex or higher risk. Specifically these conditions incorporate abnormalities of the myocardium and of the pulmonary vasculature.	This risk factor applies when the condition is diagnosed as present in the child during the admission to hospital that immediately precedes the cardiac surgery.	10.20.16 Preprocedural pulmonary hypertension, 10.13.01 Pulmonary arterial hypertension, 10.10.25 Dilated cardiomyopathy,

PRAiS2 risk group: Acquired comorbidity, applies when the condition is diagnosed / is present within the patients at any time during the admission to hospital that immediately precedes the cardiac surgery.

Code/description	Definition
101351. Pulmonary embolism	Acquired lung condition diagnosed by respiratory or thoracic specialist and confirmed by formal assessment
101400. Secondary systemic hypertension	Systemic blood pressure > 2 z-scores for age without therapy
101401. Systemic hypertension	Systemic blood pressure > 2 z-scores for age without therapy
101402. Primary (essential) systemic hypertension	Systemic blood pressure > 2 z-scores for age without therapy
101404. Systemic hypertension due to aortic arch obstruction	Systemic blood pressure > 2 z-scores for age without therapy
101501. Persistent pulmonary hypertension of the newborn (PFC),	Confirmed neonatal diagnosis, occurrence within hospitalisation pre procedure
101505. Necrotising enterocolitis	Necrotising enterocolitis class 1a or 1b, which incorporates babies with systemic signs of inflammation and abdominal clinical signs such as distension or larger than normal gastric aspirates or mild rectal bleeding but no radiological changes are included, if a general surgery specialist has seen the child and commenced a course of intravenous antibiotics and parenteral nutrition for five to seven days. Cases of severe necrotising enterocolitis with radiological signs systemic instability and bowel perforation are also included. Occurrence in hospitalisation pre-procedure.
101512. Meconium aspiration	Confirmed neonatal diagnosis, occurrence within hospitalisation pre procedure
102006. Preprocedural coagulation disorder	See STS (300) abnormal laboratory values not due to medication leading to hypocoagulable state
102007. Preprocedural renal failure	
102008. Preprocedural renal failure requiring dialysis	Need for renal replacement therapy: The child requires renal replacement therapy (peritoneal dialysis or haemofiltration) for renal failure (oligoanuria of less than 0.5 ml/kg/hour and elevated creatinine level for age) and or fluid overload in the hospital admission preprocedure.
102009. Preprocedural septicaemia	Surgical site infection and bloodstream infection: Blood stream infection includes both catheter related and non-catheter related. Cases have systemic signs of infection, a positive culture not judged to be a contaminant, and in the case of line related a catheter in place with positive cultures from the line or from the line tip when removed. Occurrence in hospitalisation preprocedure.
102012. Preprocedural neurological impairment	Neurological impairment diagnosed by specialist assessment prior to procedure
102013. Preprocedural cerebral abnormality on imaging	Head CT/MRI or other type of scan report
102017. Preprocedural tracheostomy	Tracheostomy is in situ
102018. Preprocedural seizures	Seizures occurring or medication for seizures is ongoing
102037. Preprocedural respiratory syncytial virus (RSV) infection	Confirmed viral diagnosis, occurrence within hospitalisation pre procedure

Code/description	Definition
102038. Preprocedural necrotising enterocolitis: treated medically	Necrotising enterocolitis class 1a or 1b, which incorporates babies with systemic signs of inflammation and abdominal clinical signs such as distension or larger than normal gastric aspirates or mild rectal bleeding but no radiological changes are included, if a general surgery specialist has seen the child and commenced a course of intravenous antibiotics and parenteral nutrition for five to seven days.
102039. Preprocedural necrotising enterocolitis: treated surgically	Cases of severe necrotising enterocolitis with radiological signs systemic instability and bowel perforation or other event requiring surgical intervention. Occurrence in hospitalisation pre-procedure.
140305. Psychomotor developmental delay	Developmental delay diagnosed by specialist assessment prior to procedure.
140340. Brain Abscess	Confirmed microbiological diagnosis, occurrence within hospitalisation pre procedure.
140342. Cerebrovascular accident (stroke)	CVA confirmed by specialist assessment prior to procedure.
140372. Anoxic-ischaemic encephalopathy	Neurological impairment diagnosed by specialist assessment prior to procedure.
140375. Hyperthyroidism	Acquired endocrine condition diagnosed by endocrine specialist and confirmed by formal assessment.
140390. Diabetes mellitus	Insulin dependent diabetes diagnosed prior to the procedure.
140494. Diabetes mellitus: requiring insulin	Insulin dependent diabetes diagnosed prior to the procedure.
140565. Meningitis	Confirmed microbiological diagnosis, occurrence within hospitalisation pre procedure.
158210. Kidney failure	Need for renal replacement therapy: The child requires renal replacement therapy (peritoneal dialysis or haemofiltration) for renal failure (oligoanuria of less than 0.5 ml/kg/hour and elevated creatinine level for age) and or fluid overload in the hospital admission preprocedure.
160111. Empyema	Acquired lung condition diagnosed by respiratory or thoracic specialist and confirmed by formal assessment.
160302. Lower respiratory tract infection	Confirmed microbiological diagnosis, occurrence within hospitalisation pre procedure.
160305. Lung disease	Acquired lung condition diagnosed by respiratory specialist and confirmed by formal assessment.
160310. Asthma	Acquired lung condition diagnosed by respiratory or paediatric specialist and confirmed by formal assessment.
160800. Acquired bronchial disease	Acquired condition diagnosed by respiratory or thoracic specialist and confirmed by formal assessment.
160900. Airway disease,	Acquired lung condition diagnosed by respiratory or thoracic specialist and confirmed by formal assessment.
161300. Diaphragm disorder: acquired	Acquired diaphragm condition diagnosed by respiratory or thoracic specialist and confirmed by formal assessment.
161320. Diaphragm paralysis,	Acquired diaphragm condition diagnosed by respiratory or thoracic specialist and confirmed by formal assessment.
162010. Oesophageal disorder	Acquired GI condition diagnosed by gastroenterologist or paediatric specialist and confirmed by formal assessment.

PRAiS2 risk group: Additional cardiac risk factor, applies when the condition is diagnosed as present in the child during the admission to hospital that immediately precedes the cardiac surgery.

Code/description	Definition
070001. Ventricular dyssynchrony	EF <30%; FS <15%. = poor function (i.e. severe dysfunction).
070110. Arrhythmogenic right ventricular cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment
070111. Right ventricular dysfunction	EF <30%; FS <15%. = poor function (i.e. severe dysfunction).
070610. Left ventricular dysfunction	EF <30%; FS <15%. = poor function (i.e. severe dysfunction).
070850. Ventricular myocardial noncompaction cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100701. Infectious myocarditis	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100703. Viral myocarditis	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100705. Drug induced heart muscle disease	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100708. Trypanosomal myocarditis (Chagas' disease)	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100740. Myocardial failure in end stage congenital heart disease	EF <30%; FS <15%. = poor function (i.e. severe dysfunction).
100742. Heart muscle disease in cardiac rejection	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100761. Nutritional heart muscle disease	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100771. Heart muscle disease in infant of diabetic mother	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100781. Heart muscle disease in collagen vascular/ connective tissue disorder	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100790. Myocarditis	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
100930. Ischaemic heart disease	Cardiac condition with previous infarction confirmed by ECHO, ECG and blood test values.
101001. Cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
101010. Restrictive cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
101011. Idiopathic restrictive cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
101012. Endocardial fibroelastosis	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
101013. Infiltrative cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
101020. Hypertrophic cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
101025. Dilated cardiomyopathy	Specialist cardiac diagnosis confirmed by imaging and clinical assessment.
101301. Pulmonary arterial hypertension	Pulmonary arterial systolic pressure at least 2/3 systemic by echo.
101302. Idiopathic (primary) pulmonary hypertension	Pulmonary arterial systolic pressure at least 2/3 systemic by echo.
101306. Pulmonary vascular disease	Pulmonary arterial systolic pressure at least 2/3 systemic by echo.
101308. Irreversible pulmonary vascular disease due to congenital heart disease (Eisenmenger Syndrome)	Pulmonary arterial systolic pressure greater than systemic pressure on echo.
101320. Secondary pulmonary hypertension	Pulmonary arterial systolic pressure at least 2/3 systemic by echo.

Code/description	Definition
101321. Pulmonary hypertension due to congenital systemic-to-pulmonary shunt	Pulmonary arterial systolic pressure at least 2/3 systemic by echo.
101363. Elevated lung resistance for biventricular repair (> 6 Wood units)	Pulmonary arterial systolic pressure, level as per description.
101364. Elevated lung resistance for heart transplant (> 4 Wood units)	Pulmonary arterial systolic pressure, level as per description.
101365. Elevated lung resistance for univentricular repair (> 2 Wood units)	Pulmonary arterial systolic pressure, level as per description.
101510. Transient myocardial ischaemia	EF <30%; FS <15%. = poor function (i.e. severe dysfunction).
101800. Myocardial infarction	Cardiac condition with infarction confirmed by ECHO, ECG and blood test values.
101801. Acute myocardial infarction	Cardiac condition with infarction confirmed by ECHO, ECG and blood test values.
102016. Preprocedural pulmonary hypertension	Pulmonary arterial systolic pressure at least 2/3 systemic by echo.
102034. Preprocedural myocardial infarction	EF <30%; FS <15%. = poor function (i.e. severe dysfunction).
102045. Preprocedural pulmonary hypertension (pulmonary pressure more than or equal to systemic pressure): echo data	Pulmonary arterial systolic pressure, level as per description.
102046. Preprocedural pulmonary hypertension (pulmonary pressure more than or equal to systemic pressure): catheter data	Pulmonary arterial systolic pressure, level as per description.
152231. Residual pulmonary hypertension after relief of L to R shunt	Pulmonary arterial systolic pressure at least 2/3 systemic by echo.

PRAiS2 risk group: Congenital comorbidity

Lifelong condition, presence definitively diagnosed in the child at any time, must be a specialist diagnosis (clinical genetics where genetic condition) with laboratory and or imaging evidence present.

Code/description
030102. Visceral heterotaxy (abnormal arrangement thoraco-abdominal organs)
030109. Position or morphology of thoraco-abdominal organs abnormal
030209. Lung anomaly
030214. Functionally congenital single lung
030305. Tracheobronchial anomaly
030603. Intestines malrotated
102304. Hereditary disorder associated with heart disease
140101. Chromosomal anomaly
140103. Trisomy 18 - Edwards syndrome
140104. Trisomy 13 - Pataus syndrome
140105. 45XO - Turners syndrome
140121. 22q11 microdeletion - CATCH 22
140200. Syndrome/association with cardiac involvement
140206. DiGeorge sequence
140210. Friedreich's ataxia
140217. Marfan syndrome
140219. Noonan syndrome
140221. Pompe's disease: glycogen storage disease type IIa
140228. Tuberous sclerosis
140230. Williams syndrome (infantile hypercalcaemia)
140232. Fetal rubella syndrome
140234. Duchenne's muscular dystrophy
140258. Muscular dystrophy
140262. Ehlers-Danlos syndrome
140266. Alagille syndrome: arteriohepatic dysplasia
140300. Non-cardiac abnormality associated with heart disease
140304. Non-cardiothoracic / vascular abnormality (DESCRIBE)
140306. Cystic fibrosis
140307. Diaphragmatic hernia
140308. Tracheo-oesophageal fistula

Code/description
140310. Omphalocoele
140311. Duodenal stenosis/atresia
140321. Sickle cell disease
140323. Renal abnormality
140328. Congenital coagulation disorder
140329. Thoracic / mediastinal abnormality
140333. Microcephaly
140347. Choanal atresia
140349. Tracheobronchial malacia
140352. Hypothyroidism
140391. Cerebral anomaly
140392. Connective tissue disease
140409. Kyphoscoliosis
140412. Cleft lip / palate
140485. Loeys-Dietz Syndrome (transforming growth factor beta receptor (TGFBR) gene)
140490. Von Willebrand disease
140540. Maternally derived fetal disease or syndrome associated with heart disease
140550. Major anomaly of gastrointestinal system
140601. Multiple congenital malformations
161001. Tracheal stenosis
161009. Tracheal disease

PRAiS2 risk group: Non-scoring comorbidities

Non-scoring in PRAiS2 but should be coded and submitted as part of the NCHDA data

Code/description
140102. Trisomy 21 - Downs syndrome
101600. Right ventricular abnormality: acquired
101608. Right ventricular-congestive heart failure
101640. Left ventricular abnormality: acquired
101647. Left ventricular failure
102202. Premature birth
102205. Premature birth 32-35 weeks
102206. Premature birth less than 32 weeks

PRAiS2 risk group: Severity of illness

Description	Definition
101723. Shock	See STS definitions (230-240), a state of inadequate tissue perfusion, PH<7.20, and / or Lactate>4, occurrence in hospitalisation preprocedure.
102002. Preprocedural shock	See STS definitions (230-240), a state of inadequate tissue perfusion, PH<7.20, and / or Lactate>4, occurrence in hospitalisation preprocedure.
102005. Preprocedural acidosis	See STS definitions (230), PH<7.20, and / or Lactate>4, occurrence in hospitalisation pre procedure.
102014. Preprocedural mechanical ventilatory support	Child ventilated invasively at entering the operating theatre.
102015. Preprocedural mechanical circulatory support	Extracorporeal life support when a child is on extracorporeal life support before surgery. This morbidity is defined by the presence of an extracorporeal life support system connected to the patient whether the indication was cardiac arrest, low cardiac output state, poor cardiac function, arrhythmia, residual or recurrent cardiac lesion, pulmonary including pulmonary hypertension or sepsis. Occurrence in hospitalisation preprocedure.
102031. Preprocedural shock at time of surgery (persistent)	See STS definitions (230-240), a state of inadequate tissue perfusion, PH<7.20, and / or Lactate>4, timing as per statement.
102033. Preprocedural cardiopulmonary resuscitation (< 48 hours)	Where the child receives any chest compressions or defibrillation. Occurrence in hospitalisation or preadmission within 48 hours of procedure.
110021. Cardiac Arrest	Where the child receives any chest compressions or defibrillation. Occurrence in hospitalisation preprocedure.
163001. Respiratory failure	Child ventilated invasively at entering the operating theatre.

PRAiS2 how it works

The published articles for PRAiS2 are available from here:

Incorporating Comorbidity Within Risk Adjustment for UK Pediatric Cardiac Surgery
http://dx.doi.org/10.1016/j.athoracsur.2016.12.013
http://www.annalsthoracicsurgery.org/article/S0003-4975(16)31826-4/fulltext

Improving Risk Adjustment for Mortality After Pediatric Cardiac Surgery: The UK PRAiS2 Model
http://dx.doi.org/10.1016/j.athoracsur.2016.12.014
http://www.annalsthoracicsurgery.org/article/S0003-4975(16)31828-8/fulltext

A mortality risk model to adjust for case mix in UK paediatric cardiac surgery
https://doi.org/10.3310/HSDR05230

If you are interested in how the score is calculated then see the formula/method in the supplementary information (Word document) for 'Improving Risk Adjustment for Mortality After Pediatric Cardiac Surgery: The UK PRAiS2 Model' – this has the list of variables and the corresponding coefficients to calculate the PRAiS2 score.

The specific procedures algorithm

Please see the specific procedure algorithm – Word document and R code.

Complication definitions

Acute neurological event (ANE).

To be captured using the complication code '158399. Acute neurological event during or within 30 days after cardiovascular procedure'. Code '158257. New neurological impairment (global or focal) present at discharge' is still available as additional code where applicable. For capture after both surgery and catheter procedures.

Acute neurological event (ANE)	
We recommend that children who have undergone a cardiovascular procedure have a clinical assessment as they recover during the first 48 hours and longer for those with slower recovery given that the timeline for ascertainment is up to 30 days after the procedure. If there are any clinical concerns from the bedside as to the possibility of an acute neurological event please use the definition below.	
Timeline details	**Definition criteria**
• Includes neurological morbidities that, based on best clinical judgement, arose as new findings around the time of cardiovascular procedure that were detected within 30 days of the procedure. • It is recognised that in certain circumstances such as where a child is very sick on life support, pre-procedure assessment is challenging, in these circumstances as full an evaluation as possible to be completed, incorporating serial assessments over time. • Children may have neurological events prior to a cardiovascular procedure and if this is the case please code as comorbidity, as these are not to be included as a complication: 102012. Pre-procedural neurological impairment; 102013. Preprocedural cerebral abnormality on imaging; 102018. Preprocedural seizures,	**Any or all of the following arising de novo post-procedure:** A) Physical signs of neurological injury as diagnosed by a neurologist: focal neurological deficit (includes cranial nerve deficits, hemiplegia and monoplegia), brain death, prolonged coma or significantly altered conscious level after cessation of sedatives, spinal cord ischaemia leading to impaired function, basal ganglia damage or brain stem injury leading to abnormal cough or gag reflex. B) Brain imaging reported by a neuroradiologist: a new abnormality on either cranial ultrasound, CT scan or MRI scan including: intracranial haemorrhage, extra axial haemorrhage, stroke, white matter damage, hypoxic ischaemic brain injury or uncal herniation. C) Abnormal movements as diagnosed by a neurologist: seizures requiring medical therapy to control them or new persistent movement disorder including choreiform or athetoid movement.

Prolonged pleural effusion or chylothorax

To be captured using complication code '158065. Postprocedural prolonged pleural drainage (over 10 days)'

Prolonged pleural effusion or chylothorax	
Timeline details	**Definition criteria**
Prolonged pleural effusion is a postprocedural effusion or a chylothorax with duration greater than 10 days. The diagnosis of prolonged pleural effusion or chylothorax is made from after surgery and within 30 days after the procedure.	The emphasis is on the duration of drainage. Detecting chyle in pleural, peritoneal or pericardial fluid does not count as a complication unless it is associated with prolonged drainage >10 continuous days. This includes chylous pleural effusion or significant chylous pericardial effusion or significant chylous ascites or a prolonged non-chylous effusion that necessitates thoracic drainage at least 10 days following index cardiac surgery. Chylous effusions are characterised by milky appearance and a pleural fluid white blood cell count of >1000 cells/µl with lymphocytes >80%. If the child is on normal feeds the triglyceride level in the pleural fluid will be >1.1 mmol/L or

	the ratio between the pleural triglyceride level and the serum triglyceride level will exceed 1

Extracorporeal life support

To be captured using complication code '150009. Requirement for mechanical circulatory support'

Extracorporeal life support	
Timeline details	**Definition criteria**
Extracorporeal life support within 30 days following a procedure, including the rare cases when a child was on extracorporeal life support before surgery. Preoperative ECMO is a risk factor for surgery captured by the risk stratification score When we report this complication for the audit, the patients who had preoperative ECMO can be considered in the analysis as this is a known risk factor for post operative ECMO.	This morbidity is defined by the presence of an extracorporeal life support system connected to the patient following the operation, whether it was placed in the operating theatre or in the ICU, and whether the indication was cardiac arrest, low cardiac output state, poor cardiac function, arrhythmia, residual or recurrent cardiac lesion, pulmonary including pulmonary hypertension or sepsis. Only post-cardiotomy ECMO is included in this complication. Additional complications arising on ECMO need to be captured in addition within the audit data. This applies for example to Acute Kidney Injury (defined as renal support on ECMO – for renal failure and fluid management), acute neurological event, unplanned reinterventions, wound infection. It should not apply to bleeding /chest reopening (seen as ongoing care).

Necrotising enterocolitis

To be captured using complication code '158375. Postprocedural necrotising enterocolitis - established requiring treatment'.

Necrotising enterocolitis	
Timeline details	**Definition criteria**
Necrotising enterocolitis as a new diagnosis from after surgery until 30 days following the procedure. Should not include patients with preoperative diagnosis of NEC (codes 102038. 102039.). Patients who have preoperative NEC will be recorded in NCHDA dataset as a preoperative condition (this is one of the preoperative comorbidities in the NCHDA dataset) and as such are not postoperative cases. Post-operative NEC in a child who had pre-operative NEC within 30 days is the continuation of the same condition. There is no requirement for grading. As a practical guide, however, the following simplified classification has been suggested. Moderate - any child meeting the criteria who does not need surgery and survives; severe - a child with NEC who needs surgery and/or dies.	**Systemic signs** include temperature instability, apnoea, bradycardia, raised inflammatory markers, thrombocytopenia, shock features. In NEC these are present with abdominal and or radiological signs stated below. **Abdominal - Intestinal signs** include abdominal distension, reduced or absent bowel sounds, larger than normal gastric aspirates, gastric bleeding, rectal bleeding, abdominal tenderness or cellulitis. A child who develops only mild systemic and or abdominal-intestinal signs and is treated with only with a 24-48 hour rule out course of NBM and antibiotics followed by re-starting feeds based on improvement should not be counted.

	If a general surgeon assesses the child and based on features from the systemic signs and abdominal signs elects to treat the child as NEC with NBM for minimum 5days then this case should be counted. Any child with a surgical abdomen who has a more serious picture – perforation, peritonitis, abdominal mass, is to be counted. **Radiological signs** The following are radiological signs of NEC and cases with these should be counted: pneumatosis coli, portal gas, perforation – pneumoperitoneum (excluding air under the diaphragm associated with insertion of a PD catheter in theatre or in ICU, or accidental opening of the peritoneum during the operation).

Surgical site infection

To be captured using complication code '156741. Surgical site infection requiring surgical intervention'.

Surgical site infection	
Timeline details	**Definition criteria**
Surgical site infection diagnosed within 30 days of the procedure, where the treating clinical team assesses the infection to be linked to the recent operation.	Deep surgical site infection and/or mediastinitis includes any infection of an incised wound that undergoes any re-intervention by a cardiothoracic surgeon **in a theatre environment**, such as opening of the wound, exploration and debridement of mediastinitis and false aneurysm, independent of culture positivity. If a patient returns to theatre for a surgical site infection the procedure will not be counted in the unplanned reoperation tally as it is captured here.

Unplanned reoperation or reintervention

Type 1 Complication code '124307. Unplanned reoperation/ reintervention within 30 days of procedure (excludes bleeding)'. Do not use this code for post-operative unplanned pacemaker insertions and diaphragm plications because they are captured by their own complication codes: Type 2 '110633. Procedure related complete atrioventricular block requiring permanent pacemaker system' and Type 3 '158190. Intraprocedural phrenic nerve injury (paralysed diaphragm) requiring plication of diaphragm'.

Unplanned reoperation or reintervention	
Timeline details	**Definition criteria**
Unplanned re-interventions are procedures outside the expected patient pathway, which may be undertaken at any time from the start of the postoperative admission up until 30 days following the procedure. Additional procedures or revisions undertaken within the primary trip to the operating theatre (incorporating return onto cardiopulmonary bypass) are not included in the definition of re-operation. Procedures (catheters or operations) that were planned prior to the surgery being undertaken are not to be included.	Type 1 Unplanned return to the operating room or cardiac catheter laboratory for a cardiac intervention within 30 days for procedures that were not intended during the planning phase, follow an initial primary cardiac surgery and result in "substantive alteration to heart" - incorporating cardiac bypass, cardiac non-bypass, interventional catheterisation. **Excludes:** diagnostic catheters; interventional catheters that were planned preoperatively; delayed chest closure; procedures for bleeding; ECMO/VAD; ECMO re-

	exploration; wound procedures carried out in theatre (captured separately); non-cardiac surgery procedures. Type 2 Unplanned permanent pacemaker placement as separate category Type 3 Diaphragm plication as separate category

Need for renal replacement therapy

To be captured using complication code '158213. Acute kidney injury requiring dialysis'.

Need for renal replacement therapy for renal impairment / failure and or systemic inflammatory response	
Timeline details	**Definition criteria**
Includes renal replacement therapy when initiated as a new support at any time from the start of the postoperative admission to ICU up until 30 days following the procedure.	The child requires renal replacement therapy (either peritoneal dialysis or haemofiltration) for renal failure (oligo-anuria of <0.5 ml/kg/hour and elevated creatinine level for age) and or fluid overload which may be related to systemic inflammatory response. In patients on ECMO renal support should be counted.

Cardiac arrest

To be captured using complication code '150002. Cardiac arrest following procedure'

Cardiac arrest	
Timeline details	**Definition criteria**
The included timeframe is a cardiac arrest identified during the tertiary hospital stay (either ward or ICU) following the primary surgery, not in the operating room, up to 30 days post op.	An unanticipated cardiac arrest is an event where there was no effective cardiac output detectable, and resuscitation was required. A cardiac arrest or of any duration, where the child receives any chest compressions or cardiac defibrillation for loss of cardiac output is to be included. If the heart stops as part of a planned end of life care pathway then this is not to be included.

Failed Catheter Interventions (scenarios)

Scenario 1

There is an intention to carry out a catheter intervention which does not happen for some reason, such as inability to get a guide wire across the defect. The device, stent or coil is **NOT** introduced into the patient. Only diagnostic a procedure is carried out.

Diagnosis: The diagnosis should reflect the main intended therapeutic procedure, even though not carried out.

Procedure type: '5. Diagnostic catheter'

Procedure code: '130536. Diagnostic cardiovascular catheterisation procedure with intention to treat: anatomy unsuitable'

Complication code: '159003. No postprocedural complications'

Activity count: Will appear in activity group 'diagnostic:non-surgical' and in SP '87:catheter_diagnostic' but does not qualify as part of operator procedure counts.

Scenario 2

A device, stent or coil is introduced into the patient, deployed and removed, or a device, stent or coil is introduced but is unstable and is subsequently removed.

Diagnosis: The diagnosis should reflect the intended therapeutic procedure, even though not successful

Procedure type: '3. Catheter intervention'

Procedure code: '124136. Therapeutic cardiovascular catheter procedure with failed attempt to deploy device-stent-coil'. **Code '155040. Failed attempt to implant coil-device during transcatheter intervention' should no longer be used as a procedure code.**

Complication code: '159003. No postprocedural complications'.

Activity count: Will appear in activity group 'intervention:non-surgical' and in SP '99:unallocated' but does qualify as part of operator procedure counts.

Scenario 3

A device, stent or coil is introduced into the patient and is deployed but then migrates or embolises and is either parked elsewhere in vasculature or is retrieved.

Diagnosis: The diagnosis should reflect the intended therapeutic procedure even though not successful.

Procedure type: '3. Catheter intervention'

Procedure code: Code as procedure(s) intended: i.e. ASD/PDA/VSD closure with device, stent or coil deployment. Add also if done: '124504. Transluminal retrieval of device or foreign body' as second procedure.

Complication code: one or more of:

155040. Failed attempt to implant coil-device during transcatheter intervention
155037. Embolisation of catheter introduced device
159095. Requirement for bail out surgical procedure following procedural complication
159094. Requirement for bail out transcatheter procedure following procedural complication
155065. Embolisation (dislodgement) of catheter introduced coil

155071. Embolisation of stent

155091. Stent left expanded in unplanned site after migration or embolisation

Activity count: Will appear in activity group 'intervention:non-surgical' and will appear in the appropriate SP for the procedure carried out (even though device not deployed successfully).