

Congenital heart disease specification (paediatric) 2021/22



Indicator Reference Number	Domain	Theme	Measure	Rationale	Indicator Name /Description	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Notes	Reporting Periods			
													Q1	Q2	Q3	Q4
CH01-P	Domain 4: Ensuring that people have a positive experience of care.	Outcome Measure	Patient experience and quality of care	Patient reported experience measures (PREMS) are used to assess how satisfied patients and parents are with a service. They indirectly indicate how patient centred a service is. This metric uses a specific question in the PREMS survey given to parents of children with CHD that asks them whether they are happy or not with their overall inpatient care. The PREMS survey will be available for patients/parents/carers to complete throughout the year.	Inpatient care received. (PREMS survey - positive responses)	Positive responses	Total responses	Quarterly	Quarterly	MSB	MSB	on hold	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH02-P	Domain 4: Ensuring that people have a positive experience of care.	Outcome Measure	Patient experience and quality of care	Patient reported experience measures (PREMS) are used to assess how satisfied patients and parents are with a service. They indirectly indicate how patient centred a service is. This metric uses a specific question in the PREMS survey given to parents of children with CHD that asks them whether they are happy or not with their overall outpatient care. The PREMS survey will be available for patients/parents/carers to complete throughout the year.	Outpatient care received. (PREMS survey - positive responses)	Positive responses	Total responses	Quarterly	Quarterly	MSB	MSB	on hold	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH03-P	Domain 4: Ensuring that people have a positive experience of care.	Outcome Measure	Patient experience and quality of care	Patient reported experience measures (PREMS) are used to assess how satisfied patients and parents are with a service. They indirectly indicate how patient centred a service is. This metric uses a specific question in the PREMS survey given to parents of children with CHD that asks them whether or not they received adequate information and advice at point of discharge from an inpatient stay. The PREMS survey will be available for patients/parents/carers to complete throughout the year.	Adequate information provided at discharge. (PREMS survey - positive responses).	Positive responses	Total responses	Quarterly	Quarterly	MSB	MSB	on hold	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH04-P	Domain 4: Ensuring that people have a positive experience of care.	Process	Patient experience and quality of care	Measures CH01, 02 and 03 rely on receiving enough responses to make the sample representative of the overall patient population experience. As units interested in patient feedback would be expected to encourage completion of patient experience surveys, the proportion of inpatient episodes generating a survey response will be used as a metric to assess this.	Number of surveys returned.	Number of surveys returned	Patients Discharged within time period	Quarterly	Quarterly	MSB	MSB	on hold	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH05b-P	Domain 4: Ensuring that people have a positive experience of care	Clinical process	Waiting time from referral	Minimising this period of uncertainty after the possibility of a heart abnormality is suggested during screening and is considered a key indicator of the quality of service delivered by a fetal cardiac unit.	Proportion of patients referred with suspected fetal heart disease who are offered an appointment to be seen within 3 calendar days of the referral	Of those in the denominator, the number of referrals with suspected fetal heart disease offered an appointment to be seen within 3 calendar days of the referral being made	The total number of referrals with suspected fetal heart disease seen across the network covered by the fetal cardiac service in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH06a-P	Domain 4: Ensuring that people have a positive experience of care	Clinical process	Specialist nurse contact after new fetal diagnosis	Families highly value the input of a fetal cardiac nurse specialist at the time of diagnosis of a fetal heart abnormality, therefore ensuring contact is made on the day of diagnosis is an indicator of the overall quality of the service provided.	Proportion of patients diagnosed with fetal CHD contacted by a fetal cardiac nurse specialist on the day of diagnosis	Of those patients in the denominator, the number contacted by a fetal cardiac nurse specialist on the day of diagnosis	The total number of patients diagnosed with fetal CHD in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH07-P	Domain 1: Preventing people from dying prematurely	Clinical outcome	Risk adjusted survival	The PRAIS process uses a partial risk adjustment algorithm to produce an expected 30 day survival rate for children undergoing surgery for congenital heart disease. Following an annual validation of a units data by NICOR, a calculation of the expected cumulative survival for the preceding three year period is made and compared with the observed survival. Although this is the most accurate measure of risk adjusted outcome after paediatric cardiac surgery its production is always a year after the end of the three year period concerned.	Risk adjusted survival (validated data)	Actual 30 day survival rate	PRAIS expected 30 day survival rate	3 years	Annual	Provider submitted data	Provider submitted data	If coded as an intervention on CCAD / PRAIS	N/A	N/A	N/A	Apr 18 - Mar 21
CH08-P	Domain 1: Preventing people from dying prematurely	Clinical outcome	Risk adjusted survival	All units are expected to monitor their own performance contemporaneously by running regular PRAIS analysis of their paediatric surgical procedures. Whilst the data is unvalidated, this exercise provides an early warning system for any problems that might be developing within the service. This metric provides a more contemporary measure of paediatric cardiac surgical outcomes by using a unit's actuarial / PRAIS expected 30 day survival ratio for the preceding 3 years (on a rolling basis).	Risk adjusted survival (unvalidated)	Actual 30 day survival rate	PRAIS expected 30 day survival rate	3 years rolling	Quarterly	Provider submitted data	Provider submitted data	This metric should use PRAIS2	Jul 18 - Jun 21	Oct 18 - Sep 21	Jan 19 - Dec 21	Apr 19 - Mar 22
CH09-P	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Process	Data accuracy and completeness	Data quality is acknowledged as an indicator of the importance a unit places on its outcomes and performance. The data quality index (DQI) is a measure of the accuracy and completeness of the data submitted to NICOR and is calculated by the external assessors performing the annual NICOR validation visit.	Data Quality Index (DQI)	Unit NICOR DQI	N/A	Annual	Annual	Provider submitted data	Provider submitted data	Trusts will use the report generated by the NICOR validation visit and submit once a year in Q4. Where units have a combined DQI for data from paediatrics and ACHD they should submit the same value for both dashboards and advise in the indicator comments that combined data from paediatrics and ACHD has been submitted.	N/A	N/A	N/A	Apr 21 - Mar 22
CHD10b-P	Domain 4: Ensuring that people have a positive experience of care	Clinical process	Elective surgery Cancellations	Last minute cancellations for non-clinical reasons are a measure of the quality and efficiency of a service and influence patient experience.	Proportion of elective congenital cardiac surgery procedures cancelled at the last minute for a non-clinical reason	Total number of cases in the denominator cancelled at the last minute for non-clinical reasons	The total number of elective admissions for congenital cardiac surgery (including those cancelled at the last minute for non-clinical reasons) in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data	Count all scheduled procedures that qualify as a surgical intervention for NCHD/PRAIS submission. An Elective Admission is one that has been arranged in advance. It is not an emergency admission, a maternity admission or a transfer from a Hospital Bed in another Health Care Provider. A last-minute cancellation is one that occurs on the day the patient was due to arrive, after they have arrived in hospital or on the day of their operation. Cancellation for non-clinical reasons includes unavailability of general ward or intensive care bed, unavailability of staff, because an emergency case took priority, because a surgical list ran over, due to equipment malfunction and due to an administrative error.	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22

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													Q1	Q2	Q3	Q4
CH11a-P	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical process	Reintervention rate after congenital cardiac surgery	The unplanned re-intervention rate is one measure of the quality of the surgical service.	30-day re-intervention rate following primary surgical procedure	Of those procedures in the denominator, the number resulting in unplanned re-interventions (surgery or catheter) within 30 days	The total number of primary congenital cardiac surgical procedures submitted to NCHDA in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data	Unplanned re-interventions include procedures that were not intended during the planning phase, follow an initial primary cardiac surgery and result in "substantive alteration to the heart" incorporating cardiac bypass, cardiac non bypass, pacemaker placement, interventional catheterisation and include diaphragm plication (which are not related to the heart itself). The definition does not include mechanical support or other non-cardiac surgery procedures and specifically excludes those procedures listed in the metrics definitions in appendix 1. Denominator note: Please exclude those procedures submitted to NCHDA that are classified as 'Minor and Excluded Procedures'.	Jan 21 - Mar 21	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21
CH12bii-P	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical outcome	Congenital cardiac surgery - significant procedure related complications	The frequency of significant procedure related complications following congenital cardiac surgical services.	30-day complication rate following primary surgical procedure	Of those procedures in the denominator, the number resulting in procedure-related complications within 30 days	The total number of primary congenital cardiac surgical procedures submitted to NCHDA in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data	Numerator note: Please see appendix 2 for the list of significant procedure related complications. Please also count any complications that occurred during the same admission. Denominator note: Please exclude those procedures submitted to NCHDA that are classified as 'Minor and Excluded Procedures'.	Jan 21 - Mar 21	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21
CH13a-P	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical outcome	Unplanned re-intervention rate - congenital cardiac catheter intervention	The unplanned re-intervention rate is one measure of the quality of the congenital catheter intervention service. The number of patients having one or more unplanned re-intervention within 30 days of a planned congenital cardiac catheter procedure will be used to measure this.	30-day re-intervention rate following primary catheter intervention procedures	Of those procedures in the denominator, the number resulting in catheter interventions within 30 days	The total number of primary catheter intervention procedures submitted to NCHDA in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data	Unplanned re-interventions include procedures that were not intended during the planning phase, follow an initial primary cardiac intervention and result in "substantive alteration to the heart" incorporating cardiac bypass, cardiac non bypass, pacemaker placement and interventional catheterisation. The definition does not include mechanical support or other non-cardiac surgery procedures and specifically excludes those procedures listed in the metric definitions in appendix 1.	Jan 21 - Mar 21	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21
CH14bii-P	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical outcome	Congenital cardiac catheter intervention procedures - significant procedure related complications	The frequency of significant procedure related complications after congenital cardiac intervention procedures is one measure of the quality of the congenital cardiac catheter intervention service.	30-day complication rate following primary catheter intervention procedures	Of those procedures in the denominator, the number resulting in complications within 30 days	The total number of primary catheter intervention procedures submitted to NCHDA in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data	Numerator note: Please see appendix 3 in the metric definitions sheets for the list of the significant procedure related complications. Please also count any complications that occurred during the same admission.	Jan 21 - Mar 21	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21
CH15-P	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Outcome measure	Infection control	Hospital acquired infection rate is a measure of patient safety and the quality of inpatient care. This will be assessed by the proportion of patients acquiring Clostridium difficile during an inpatient stay under the care of the congenital cardiac service.	Hospital Acquired Clostridium difficile. Proportion of inpatients under care of the paediatric cardiac service acquiring new positive Clostridium difficile cultures	Number of inpatients under care of the paediatric cardiac service acquiring new positive Clostridium difficile cultures	Total number of inpatient stays under the paediatric cardiac service	Quarterly	Quarterly	Provider submitted data	Provider submitted data	An inpatient stay is defined as a hospital episode consisting of formal admission, allocation of a bed and discharge.	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH16-P	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Outcome measure	Infection control	Hospital acquired infection rate is a measure of patient safety and the quality of inpatient care delivered. This will be assessed by the proportion of patients acquiring MRSA during an inpatient stay under the care of the congenital cardiac service.	Hospital Acquired MRSA. Proportion of inpatients under care of the paediatric cardiac service acquiring new positive MRSA cultures	Number of inpatients under care of the paediatric cardiac service acquiring new positive MRSA cultures	Total number of inpatient stays under the paediatric cardiac service	Quarterly	Quarterly	Provider submitted data	Provider submitted data	An inpatient stay is defined as a hospital episode consisting of formal admission, allocation of a bed and discharge.	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH17-P	Domain 4: Ensuring that people have a positive experience of care	Outcome measure	Complaints	Formal written complaints are a measure of patient dissatisfaction and indirect measure of patient experience. The proportion of inpatient care episodes resulting in a written complaint will be used to assess this. Units must submit their own data.	Formal complaints involving inpatients	Number of formal written complaints involving patients admitted under the care of the paediatric cardiac service	Total number of inpatient stays under the paediatric cardiac service	Quarterly	Quarterly	Provider submitted data	Provider submitted data	An inpatient stay is defined as a hospital episode consisting of formal admission, allocation of a bed and discharge.	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH20-P	Domain 4: Ensuring that people have a positive experience of care	Outcome Measure	Outpatient delays	tbc	Proportion of patients waiting over the planned time for their follow up appointment	Of those in the denominator, the number of patients who waited over the planned time for the appointment	The total number of patients seen at a follow up outpatients appointment in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data	Surgical Centre only	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22
CH21-P	Domain 4: Ensuring that people have a positive experience of care	Outcome Measure	Outpatient delays	tbc	Average waiting time from the planned appointment to the actual follow up appointment for patients waiting more than the planned time for their follow up appointment	The total number of days from planned follow up appointment to the actual appointment	The total number of patients seen at a follow up outpatients appointment who waited longer than the planned time in the reporting period	Quarterly	Quarterly	Provider submitted data	Provider submitted data	Surgical Centre only	Apr 21 - Jun 21	Jul 21 - Sep 21	Oct 21 - Dec 21	Jan 22 - Mar 22

Data collection has been approved by the Review of Central Returns - ROCR
ROCR/OR/2230/001/MAND

Conges Appendix 1

Metrics CH11a-P & CH13a-P

Procedure codes specifically excluded are listed below:

- 120625. Transluminal RV biopsy
- 123200. Post-operative procedure
- 123206. Lung biopsy procedure
- 123214. DC cardioversion
- 123217. Parietal pleurectomy
- 123218. Post-operative procedure to control bleeding
- 123221. Cardiac procedure (DESCRIBE)
- 123240. Pericardiocentesis
- 123241. Pericardiocentesis - open
- 123243. Pericardiocentesis - transcatheter
- 123246. Pericardial window creation

- 123253. Pericardial biopsy

- 123259. Procedure involving pericardium (DESCRIBE)

- 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
- 123713. Single lung transplant
- 123720. Double lung transplant

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- 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
- 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
126548. Sternal wire removal from previous sternotomy
126560. Delayed closure of sternum
126572. Open excision of pleural lesion
126600. Lung procedure
126601. Lung decortication
126602. Lung mass excision
126605. Lung lobectomy
126606. Pneumonectomy
126607. Lung sequestration repair
128000. Thoracic / mediastinal procedure (DESCRIBE)
130103. Transoesophageal echocardiography
130501. Diagnostic catheterisation procedure
130505. Diagnostic cardiovascular catheterisation procedure

Conge **Appendix 2**

Metric CH12bii-P

The number of congenital cardiac surgical procedures that are followed by one or more of the complications as listed:

- 158213. Acute kidney injury requiring haemofiltration or haemodialysis
- 150009. Requirement for mechanical circulatory support (including ECMO and VAD)
- 158375. Postprocedural necrotising enterocolitis - established requiring treatment
- 156741. Surgical site infection requiring surgical intervention
- 158064. Prolonged pleural drainage >7days
- 158190. Phrenic nerve injury requiring plication of hemidiaphragm
- 158086. Postprocedural requirement for tracheostomy
- 110633. Postprocedural complete atrioventricular block requiring permanent pacemaker

Congenital **Appendix 3**

Metric CH14bii-P

The number of congenital cardiac catheter intervention procedures that are followed by one or more of the complications listed as below:

- 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
- 155061. Coronary arterial compression following transluminal device implantation
- 155037. Embolisation of catheter introduced device
- 155052. Erosion of or into cardiac structure by implanted transcatheter device
- 155071. Embolisation of stent
- 155065. Embolisation (dislodgment) of catheter introduced coil
- 155091. Stent left expanded in unplanned site after migration, embolisation or failure to deliver to intended site.
- 155078. Rupture of conduit or vessel following stent implantation
- 155154. Mechanical haemolysis due to transcatheter implanted device or coil, requiring transfusion

- 155040. Failed to implant coil/device during transcatheter intervention (device removed from packaging)

- 158375. Postprocedural necrotising enterocolitis - established requiring treatment

- 158257. Postprocedural new permanent neurological impairment (global or focal)

- 159094. Requirement for bailout transcatheter procedure following procedural complication
- 159095. Requirement for bailout surgical procedure following procedural complication