

Linkage of National Congenital Heart Disease Audit data to hospital, critical care and mortality national data sets to enable research focused on quality improvement

Supplemental Tables

Table S1 NCHDA fields obtained.

NCHDA field name	Description
1.00 Data Set Version	The version of the data set the data was collected for and submitted to NICOR
1.01 Hospital identifier	The identifier allocated to the hospital by NICOR. The software should set this field without any user involvement.
1.07 Patient Gender	Identifies the genotypical sex of the patient.
1.08 Patient Ethnic Group	Identifies the patient's ethnic origin.
1.09 Patient Admin status	Type of admission, i.e. from UK public health service or other mode of entry to the service
2.01 Diagnosis	The preprocedural diagnosis of the patient
2.02 Previous Procedure	Relevant previous procedures
2.03 Weight	The patients weight in kg at the time of procedure to two decimal places.
2.03b Height	Height at time of procedure in cm
2.04 Antenatal Diagnosis	Diagnosis detected prior to birth from prenatal scans
2.05 Preprocedure seizures	Any preprocedural convulsions/seizures requiring medication
2.06b Comorbidity present	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.
2.07 Comorbid Conditions	Identifies the specific comorbid condition
2.08 Preprocedure systemic ventricular ejection fraction	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.
2.09 Preprocedure subpulmonary ventricular ejection fraction	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.
3.01b Procedure urgency	Categorises the patient in terms of the urgency
3.01c Unplanned reoperation	Used to identify cases that aren't part of the planned pathway for that patient.
3.04 First operator grade	The grade of the secondary operator or assistant.
3.06 First assistant grade	The grade of the secondary operator or assistant.
3.07 Type of Procedure	Defines the group the procedure should be included in.
3.08 Sternotomy Sequence	Incremental count of the number of sternotomies that the patient has undergone.
3.09 Operation performed	The EPCC short codes that describe the procedure
3.10 Total bypass time	The total duration of cardiopulmonary bypass used during the procedure.
3.11 Total bypass cross clamp time	The total duration of aortic cross clamp during the procedure.
3.12 Total circulatory arrest time	The total duration of circulatory arrest during the procedure.
3.13 Catheter procedure duration	The operative time taken.
3.14 Total fluoroscopy time	The total time fluoroscopy was used during the procedure
3.15 Total fluoroscopy dose	The total fluoroscopy dose during the procedure

3.16 Procedure Report Or Comment	Accompanying text that can help describe the procedure in cases where coding is thought to be inadequate.
4.03 Discharge status	The status of the patient at discharge from your hospital.
4.04 Discharge Destination	The immediate destination following discharge from your hospital
4.05 Postprocedure seizures	Any postprocedural convulsions/seizures requiring medication
4.07 Duration of postoperative intubation	Duration of postoperative intubation associated with a procedure.
4.08 Postoperative complications	Significant postoperative complications following surgery
4.09 Attribution of death	The attribution of death to a procedure
5.01 Device Manufacturer	The manufacturer of any implanted devices.
5.02 Device model	The model numbers of any implanted device.
5.04 Device Size	The size of any devices implanted.
6.01 Preprocedure NYHA status	The patient's preprocedural NYHA status.
6.02 Preprocedure smoking status	The patient's preprocedural smoking status
6.03 Preprocedure diabetes	The patient's preprocedural diabetes status
6.04 History of pulmonary disease	The patient's preprocedural pulmonary disease status
6.06 Preprocedural ischaemic heart disease	The patient's preprocedural ischaemic heart disease status
7.01 Preprocedural valve or septal defect or vessel size	The preprocedural size of the valve or septal defect or vessel size
7.02 Sizing balloon used for septal defect closure Y/N	Was a sizing balloon used for septal defect occlusion
7.03 Number of stents or coils	The number of stents and/or coils deployed
7.04 Catheterisation complication severity rating	Classifies the severity of the most major catheter complication.
7.05 Catheterisation complications	Significant postprocedural complications following a cardiac catheter
LAUNCHES derived field name	Description
LAUNCHESrecID	LAUNCHES record identifier
LAUNCHESpatID	LAUNCHES patient identifier
LAUNCHESpatID_rev	LAUNCHES patient identifier revised
Qcode	Record identifiers' quality code
dob.year	Year of birth derived from 1.06 Patient Date of Birth
dob.month	Month of birth derived from 1.06 Patient Date of Birth
country	Country of patient's residence derived from 1.10 Patient Post Code
IMD2004.rank	IMD2004 rank of patient's residence derived from 1.10 Patient Post Code
IMD2004.decile	IMD2004 decile of patient's residence derived from 1.10 Patient Post Code
IMD2007.rank	IMD2007 rank of patient's residence derived from 1.10 Patient Post Code
IMD2007.decile	IMD2007 decile of patient's residence derived from 1.10 Patient Post Code
IMD2010.rank	IMD2010 rank of patient's residence derived from 1.10 Patient Post Code
IMD2010.decile	IMD2010 decile of patient's residence derived from 1.10 Patient Post Code
IMD2015.rank	IMD2015 rank of patient's residence derived from 1.10 Patient Post Code
IMD2015.decile	IMD2015 decile of patient's residence derived from 1.10 Patient Post Code
Raop	Age in years (4 decimal places) at procedure derived from 3.01 Date/Time procedure
RFLAGtop	Record FLAG: time of procedure present?
Raodis	Age in years (4 decimal places) at discharge derived from 4.01 Date of Discharge
Raad	Age in years (4 decimal places) at death derived from 4.02 Date of Death

Note: The NCHDA linked data and linkage quality report were received on 23 September 2019. The revised ages and anonymised patient key identifiers were received on 27 February 2019.

Table S2 HES inpatient (HES APC) fields obtained.

HES Inpatient field name	Description
ADMIFLAG	Admission episode flag
ADMIMETH	Method of admission
ADMISORC	Source of admission
AEKEY	Record identifier
BIRSTAT_N	Birth status
CLASSPAT	Patient classification
DIAG_NN	All Diagnosis codes
DISDEST	Destination on discharge
DISFLAG	Discharge episode flag
DOMPROC*	Trust derived dominant procedure
ENCRYPTED_HESID	Patient identifier - HES generated (encrypted version)
EPIKEY	Record identifier
EPIORDER	Episode order
ETHNOS*	Ethnic category
ETHRAW*	Ethnic character (audit version)
FIRSTREG	First regular day or night admission
HRG_N.N	Healthcare resource group: version 3.1
HRGNHS	Trust derived HRG value
HRGNHSVN	Version No. of Trust derived HRG
IMD04	IMD Index of Multiple Deprivation
IMD04_DECILE	IMD Decile Group
IMD04RK	IMD Overall Rank
MAINSPEF	Main specialty
OPERTN_NN*	Primary Operative Procedure Codes
PROCODE5	Provider code (5 character)
PROCODET	Provider code of treatment
PROTYPE	Provider type
RESGOR	Government Office region of residence
RESGOR_ONS	Government office region of residence (ONS)
RURURB_IND	Rural/Urban Indicator
SEX*	Sex of patient
SEXBABY*	Sex of baby
SITEDIST	Distance between patient's LSOA and provider site code of treatment
SITETRET*	Site code of treatment
SPELEND	End of spell indicator
SUSCOREHRG	SUS generated Core Spell HRG
SUSHRG	SUS generated HRG
SUSHRGVERS	SUS generated HRG version number
TRETSPEF*	Treatment specialty
LAUNCHES derived field name	Description
MATCH_RANK	Quality code of the linkage between the NCHDA record and the HES ID
STUDY_ID	LAUNCHES record ID of the linked NCHDA record
MY_DOB	Date of Birth - month and year

age_admission	Age at admission to hospital to 4 decimal places (calculated from ADMIDATE and DOB)
age_epistart*	Age at episode start to 4 decimal places (calculated from ADMIDATE and DOB)
age_discharge	Age at discharge from hospital to 4 decimal places (calculated from DISDATE and DOB)

Note: The HES/ONS linked data and linkage quality report were received on 17 September 2020.

Records with a star (*) were obtained on 08 February 2022.

Table S3 HES Outpatient (HES OP) fields obtained.

HES Outpatient field name	Description
ATENTYPE	Attendance type
ATTENDED	Attended or did not attend
ATTENDKEY*	Record identifier
DIAG_NN	Diagnosis
ENCRYPTED_HESID	Patient identifier - HES generated (encrypted version)
ETHNOS*	Ethnic category
ETHRAW*	Ethnic character (audit version)
FIRSTATT	First attendance
HRGNHS	Trust derived HRG value
HRGNHSVN	Version No. of Trust derived HRG
IMD04	IMD Index of Multiple Deprivation
IMD04_DECILE	IMD Decile Group
IMD04RK	IMD Overall Ranking
LOCTYPE	Location type
MAINSPEF	Main specialty
OUTCOME	Outcome of attendance
PRIORITY	Priority type
PROCODE5	Provider code (5 character)
PROCODET	Provider code of treatment
PROTYPE	Provider type
PROVDIST	Distance between patient's LSOA and provider
REFSOURC	Source of referral
RESGOR	Government Office region of residence
RESGOR_ONS	Government office region of residence (ONS)
RURURB_IND	Rural / urban indicator
SEX*	Sex of patient
SITEDIST	Distance between patient's LSOA and provider site code of treatment
SITETRET*	Site code of treatment
SUSHRG	SUS generated HRG
SUSHRGVERS	SUS generated HRG version number
TRETSPEF	Treatment specialty
LAUNCHES derived field name	Description
MATCH_RANK	Quality code of the linkage between the NCHDA record and the HES ID
STUDY_ID	LAUNCHES record ID of the linked NCHDA record
MY_DOB	Date of Birth - month and year
age_appointment_OP	Age at outpatient appointment date to 4 decimal places (calculated from APPTDATE and DOB)

Note: The HES/ONS linked data and linkage quality report were received on 17 September 2020.

Records with a star (*) were obtained on 08 February 2022.

Table S4 HES A&E (HES AE) fields obtained.

HES A&E field name	Description
AEARRIVALMODE	Arrival mode
AEATTEND_EXC_PLANNED	Attendances excluding planned
ADEPTTYPE	Department type
AEKEY	Record identifier
DIAG_NN*	A&E diagnosis
DIAG2_NN	A&E diagnosis: 2 character
DIAGSCHEME*	Diagnosis Scheme in Use
DOMPROC	Dominant procedure
ENCRYPTED_HESID	Patient identifier – HES generated (encrypted version)
EPIKEY	Record identifier
ETHRAW*	Ethnic category
HRGNHS	Trust derived HRG value
HRGNHSVN	Version No. of trust derived HRG
IMD04	IMD Index of Multiple Deprivation
IMD04_DECILE	IMD Decile group
IMD04RK	IMD Overall rank
PROCODE5	Provider code (5 character)
PROCODET	Provider code of treatment
PROTYPE	Provider type
PROVDIST	Distance between patient's LSOA and provider
REGGOR	Government Office region of residence
REGGOR_ONS	Government office region of residence (ONS)
RURURB_IND	Rural/Urban Indicator
SEX*	Sex of patient
SITEDIST	Distance between patient's LSOA and provider site code of treatment
SITETRET*	Site code of treatment
SUSHRG	SUS generated HRG
SUSHRGINFO	SUS generated HRG for information
SUSHRGVERINFO	SUS generated HRG for information version number
SUSHRGVERS	SUS generated HRG version number
LAUNCHES derived field name	Description
MATCH_RANK	Quality code of the linkage between the NCHDA record and the HES ID
STUDY_ID	LAUNCHES record ID of the linked NCHDA record
MY_DOB	Date of Birth - month and year
age_arrival_AE	Age at arrival to A&E to 4 decimal places (calculated from ARRIVALDATE and DOB)

Note: The HES/ONS linked data and linkage quality report were received on 17 September 2020. Records with a star (*) were obtained on 08 February 2022.

Table S5 ONS mortality fields obtained.

ONS field name	Description
ID	Patient identifier for ONS data – HES generated (encrypted)
STUDY_ID	LAUNCHES record ID of the linked NCHDA record
ENCRYPTED_HESID	Patient identifier – HES generated (encrypted version)
HES_ONS_Match_Rank	Quality code of the linkage between the ONS and HES IDs
age_death*	Age of death to 4 decimal places
life_status*	Life status (A=Alive, D=Death)
age_life_status*	Age at life status to 4 decimal places
COMMUNAL_ESTABLISHMENT_NAME	Communal Establishment (with place of death from the communal establishment lookup reference data)

Note: The HES/ONS linked data and linkage quality report were received on 17 September 2020. Records with a star (*) were obtained on 08 February 2022, including an update on age of death.

Table S6 PICANet fields obtained.

PICANet field name	Description
AcuteNec	Acute Necrotising Enterocolitis (NEC) main reason for ICU admission 1 indicates a positive response
AdType	Type of admission to PICU
bp_PrimReason	Primary reason for admission, a PIM variable used as an input value for PIM2, The PICANet data set stopped collecting this variable when PIM3 data collection was initiated. This variable is used if present, if not present this value can be assumed as recovering from surgery if the PIM3 variables indicate that the patient was recovering from surgery
Cardiomyocarditis	Cardiomyopathy or myocarditis 1 indicates a positive response
CareAreaAd	Care area of admission - expected if Source of admission is 1 or 2
ClinicalCodeType	The type of clinical code supplied to PICANet
Diagnosis	Read CTV3 clinical code
DiagnosticGroup	As Per PICANet annual report data set reporting categories - only included for primary diagnosis
DisPalCare	Discharged for palliative care
EcmoDaysDays	Number of days that the patient received Extracorporeal membrane oxygenation (ECMO)
ElectiveAd	Elective admission, 1 indicates that the admission was elective
Ethnic	Recorded ethnic category of record from
FU30DisStatus	Follow up 30 days post discharge
FU30Location	Location at 30 days following discharge
Gest	Gestational age in weeks, expected between 24 and 42, 99 indicates that the value is unknown
HiFlowNasalDays	Number of days that the patient received High flow nasal cannula therapy
HypoPlas	Hypoplastic left heart syndrome 1 indicates a positive response
IcpDeviceDays	Number of days that the patient used ICP-intracranial pressure monitoring, Intraventricular catheter or external ventricular drain
InflnotropeDays	Number of days that the patient received Continuous infusion of inotrope, vasodilator or prostaglandin
IntTracheostomy	Tracheostomy performed
Intubation	Patient was intubated
InvasiveVentilationDay	Number of days that the patient was invasively ventilated based on the PICANet daily interventions fields Invasive ventilation via endotracheal tube, Invasive ventilation via tracheostomy tube, Advanced ventilatory support (jet ventilation) and Advanced ventilatory support (oscillatory ventilation)
IsReAd	This record is an emergency readmission
LvadDays	Number of days that the patient used Ventricular assist device (VAD)
MechVent	Mechanical ventilation
MedHistEvid	Is evidence available of past medical history?
Mult	Multiplicity of birth, Expecting a value between 1 and 4m 9 indicates that the value is unknown
NonInvasiveVentilationDay	Number of days that the patient received Non-invasive ventilatory support
PICANetPatientID	Unique identifier for each patient in the PICANet database - pseudonymised from PICANet PatientID
PICANetRecordID	Unique identifier for each PICANet Admission Event - pseudonymised from PICANet EventID
PICUOrg	PICANet Organisation identifier
PICUOrgName	Name of PICANet organisation
PIM	Original PIM score

PIM2	Original PIM2 score
PIM2r2011	PIM2 recalculated 2011
PIM2r2012	PIM2 recalculated 2012
PIM2r2013	PIM2 recalculated 2013
PIM2r2014	PIM2 recalculated 2014
PIM2r2015	PIM2 recalculated 2015
PIM2r2016	PIM2 recalculated 2016
PIM2r2017	PIM2 recalculated 2017
PIM3	Original PIM3 score
PIMr	PIM recalculated
PrecedCpr	Cardiac arrest before ICU admission 1 indicates a positive response
PreceHospCardArr	Cardiac arrest OUT of hospital 1 indicates a positive response
PrevicuAd	Previous ICU admission
RenalSupportDays	Number of days that the patient has received peritoneal dialysis, Haemofiltration, Haemodialysis, Plasma filtration or Plasma exchange
Retrieval	Was the patient retrieved to the organisation
SpontCerebHaem	Spontaneous cerebral haemorrhage 1 indicates a positive response
TotalUnplannedExtubations	The total number of times during an admission that there was dislodgement of the ETT from the trachea, without the intention to extubate immediately and without the presence of airway competent clinical staff appropriately prepared for the procedure occurs
TrachDays	Number of Days that the patient had a Tracheostomy cared for by nursing staff
UnitDisDest	Destination following discharge
UnitDisStatus	Status at discharge
UZ01Z_days	number of days the patient received care at UZ01Z
XB01Z_days	number of days the patient received care at XB01Z
XB02Z_days	number of days the patient received care at XB02Z
XB03Z_days	number of days the patient received care at XB03Z
XB04Z_days	number of days the patient received care at XB04Z
XB05Z_days	number of days the patient received care at XB05Z
XB06Z_days	number of days the patient received care at XB06Z
XB07Z_days	number of days the patient received care at XB07Z
XB09Z_days	number of days the patient received care at XB09Z
LAUNCHES derived field name	Description
AgeYrAdmit	Age at admission in years to 4 decimal places
AgeYrDeath	Age at death in years to 4 decimal places
AgeYrDischarge	Age at discharge in years to 4 decimal places

Note: The PICANet linked data and linkage quality report were received on 17 October 2019.

Table S7 ICNARC-CMP fields obtained.

ICNARC-CMP field name	Description
AP2aps	APACHE II acute physiology score
AP2probIC3	APACHE II (ICNARC 2013) probability
AP2score	APACHE II score
CMPrecordID	CMP (ICNARC) record ID for LAUNCHES
IM2018prob	Recalibrated 2018 model predicted mortality probability
IMscore	ICNARC model physiology score
MEWS	Modified Early Warning Score
ODacid_v3	Metabolic acidosis organ dysfunction
ODcardio_v3	Cardiovascular organ dysfunction
ODhaem_v3	Haematological organ dysfunction
ODrenal_v3	Renal organ dysfunction
ODresp_v3	Respiratory organ dysfunction
POPScore	Pancreatitis Outcome Prediction (POP) Score
SIRShr_v3	SIRS tachycardia flag
SIRSrr_v3	SIRS tachypnoea
SIRStemp_v3	SIRS fever or hypothermia flag
SIRSwbc_v3	SIRS white blood cell flag
SOFAcadio_v3	SOFA cardiovascular score (0-2)
SOFAcoag_v3	SOFA coagulation score (0-2)
SOFAincr_v3	SOFA increase from baseline (0-2 per organ)
SOFAliver_v3	SOFA liver score (0-2)
SOFAneuro_v3	SOFA neurological score (0-2)
SOFAod_v3	SOFA number of organ dysfunctions (2+ each organ)
SOFArenal_v3	SOFA renal score (0-2)
SOFAresp_v3	SOFA respiratory score (0-2)
SOFAtot_v3	SOFA total score (0-2 per organ)
acsd	Calendar days of advanced cardiovascular support while in your unit
admtype	Type of admission
ahlos	All hospital length of stay, days
ahlosa	Any hospital length of stay after discharge from icu, days
ahlosb	Any hospital length of stay before admission to icu, days
ahsurv	Ultimate hospital survival
arsd	Calendar days of advanced respiratory support while in your unit
aulos	All unit length of stay, days
ausurv	Ultimate unit survival
bcsd	Calendar days of basic cardiovascular support while in your unit
bmi	BMI (kg/m ²)
brsd	Calendar days of basic respiratory support while in your unit
bsdtp	Brainstem death declared
ccl0d	Days of level 0 care while in your unit
ccl1d	Days of level 1 care while in your unit
ccl2d	Days of level 2 care while in your unit
ccl3d	Days of level 3 care while in your unit

classns	Classification of surgery
cpr_v3	Cardiopulmonary resuscitation within 24 hours prior to admission to your unit
crpreg	Admission currently/recently pregnant
curb65	CURB 65 score
delay	Length of delay (days)
deldis12	Delayed discharges (12 hour delay)
deldis24	Delayed discharges (24 hour delay)
deldis24_exooh	Delayed discharges (24 hour delay), excluding night discharges
deldis4	Delayed discharges (4 hour delay)
dep	Dependency prior to admission to acute hospital
desc	ICNARC diagnostic category description (raicu1)
desth_v3	Destination following discharge from your hospital
dis	Status at discharge from your unit
dobest	Date of birth estimated
dsd	Calendar days of dermatological support while in your unit
ethnic	Ethnicity
gsd	Calendar days of gastrointestinal support while in your unit
hloca	Hospital housing non-transient location (in)
hlocd	Hospital housing non-transient location (out)
hrg	Healthcare Resource Group
htloca	Hospital housing transient location (in)
imd2015	Quintile of English IMD 2015/Welsh IMD 2014/NI MDM 2010
imd_error	Postcode available for derivation of IMD
infection_v3	Infection
itw_v3	Treatment withheld/withdrawn
kdigo_mdrd75	AKI stage (KDIGO)
korgfail	Number of Knaus organ system failures
leva	Highest level of care received in the first 24 hours in your unit
loca	Location (in)
locd	Location (out)
lsd	Calendar days of liver support while in your unit
nlb	Number of live births (babies) from recent pregnancy
npcs	Number of previous Caesarean sections excluding most recent pregnancy
nplsb	Number of live births (babies) or stillbirths from previous pregnancies
nsb	Number of stillbirths from recent pregnancy
nsd	Calendar days of neurological support while in your unit
nuaib	Number of unit-acquired infections present in blood
orgdys_v3	Number of organ dysfunctions
outrp	Outcome of recent pregnancy
ploca	Prior location (in)
raicu1	Primary reason for admission to your unit
rdis_v3	Reason for discharge from your unit
readearly	Early readmissions
readlate	Late readmissions
resa	Residence prior to admission to an acute hospital
resd	Residence post-discharge from your hospital

rsd	Calendar days of renal support while in your unit
sepsis3_v3	Sepsis-3
sepsis_v3	Sepsis
sirs_v3	SIRS criteria count
soha	Sector of other hospital (in)
sohd	Sector of other hospital (out)
sshock3_v3	Septic shock (Sepsis-3)
tnessd	Timeliness of discharge from your unit
typeiha	Type of adult ICU/HDU (in)
typeihd	Type of adult ICU/HDU (out)
version	ICMPDS version number
withinsh	Readmission within same hospital stay
wkg	Weight (kg)
yhlos	Your hospital length of stay, days
yhlosa	Your hospital length of stay after discharge from icu, days
yhlosb	Your hospital length of stay before admission to icu, days
yhsurv	Your hospital survival
yulos	Your unit length of stay, hours
yusurv	Your unit survival
LAUNCHES derived field name	Description
age_ah	Age at admission to hospital (not time-based, 4 decimal places)
age_aicu	Age at admission to ICU (time-based, 4 decimal places)
age_dbsd	Age at declaration of brainstem death (time-based, 4 decimal places)
age_dh	Age at discharge from hospital (not time-based, 4 decimal places)
age_dicu	Age at discharge from ICU (time-based, 4 decimal places)
age_oah	Age at original admission to hospital (not time-based, 4 decimal places)
age_oaicu	Age at original admission to ICU (not time-based, 4 decimal places)
age_od	Age at death (time-based, 4 decimal places)
age_tw	Age when decision to withdraw treatment made (time-based, 4 decimal places)
age_udicu	Age at death (time-based, 4 decimal places)
Country	Country
Mob	Month of birth
qcode_CMP	Quality of CMP record for linkage
Yob	Year of birth

Note: The ICNARC-CMP linked data and linkage quality report were received on 4 December 2019.

Table S8 NCHDA to PICANet lookup of organisations, used to match hospital patient identifiers.

NCHDA organisation name	PICANet organisation name
ACH. Alder Hey Hospital	PIC010. Liverpool Alder Hey
BCH. Birmingham Children's Hospital	PIC001. Birmingham Children's Hospital
BRC. Bristol Children's Hospital	PIC003. Bristol Royal Hospital for Children
FRE. Freeman Hospital	PIC021. Newcastle Freeman Hospital
GEO. St George's Hospital	PIC015. London St George's Hospital
GOS. Great Ormond Street Hospital for Children	PIC011/PIC039. London Great Ormond Street Hospital PICU_NICU/CCCU
GRL. Glenfield Hospital	PIC008. Leicester Glenfield Hospital
GUY. Evelina London Children's Hospital	PIC012. London Evelina Children's Hospital
HRI. Hull Royal Infirmary	PIC028. Hull Royal Infirmary
KCH. King's College Hospital	PIC013. London Kings College Hospital
LGI. Leeds General Infirmary	PIC006. Leeds General Infirmary
MRI. Manchester Royal Infirmary	PIC018. Manchester Royal Children's Hospital
NGS. Northern General Hospital	PIC025 / PIC029. Sheffield General NICU/PICU
NHB. Royal Brompton Hospital	PIC014. London Royal Brompton Hospital
RAD. John Radcliffe Hospital	PIC024. Oxford John Radcliffe Hospital
SBH. St Bartholomew's Hospital	PIC032. London The Royal London Hospital
SGH. Southampton General Hospital	PIC026. Southampton Children's Hospital
STM. St Marys Hospital, Paddington	PIC016. London St Mary's Hospital
STO. University Hospital of North Staffordshire	PIC027. Stoke on Trent - Royal Stoke University Hospital
UHW. University Hospital of Wales	PIC005. Cardiff Noah's Ark children's Hospital for Wales

Table S9 HES 8-step linkage method.

Match Rank	NHS number	DoB	Sex	Postcode	Extra Condition
1	Exact	Exact	Exact	Exact	
2	Exact	Exact	Exact		
3	Exact	Partial	Exact	Exact	
4	Exact	Partial	Exact		
5	Exact			Exact	
6		Exact	Exact	Exact	where NHS does not contradict the match and DOB is not 1 January and the POSTCODE is not in the 'ignore' list
7		Exact	Exact	Exact	where NHS does not contradict the match and DOB is not 1 January
8	Exact				

Note: Sex was not part of the NCHDA identifiers approved for linkage, so only steps 5 and 8 were used.

Table S10 ICD-10 diagnosis codes indicating congenital heart disease (CHD) or potential mistakenly coded acquired (non-rheumatic) heart disease.

ICD-10 congenital heart disease code	Description
Q20	Congenital malformations of cardiac chambers and connections
Q20.0	Common arterial trunk
Q20.1	Double outlet right ventricle
Q20.2	Double outlet left ventricle
Q20.3	Discordant ventriculoarterial connection
Q20.4	Double inlet ventricle
Q20.5	Discordant atrioventricular connection
Q20.6	Isomerism of atrial appendages
Q20.8	Other congenital malformations of cardiac chambers and connections
Q20.9	Congenital malformation of cardiac chambers and connections, unspecified
Q21	Congenital malformations of cardiac septa
Q21.0	Ventricular septal defect
Q21.1	Atrial septal defect
Q21.2	Atrioventricular septal defect
Q21.3	Tetralogy of Fallot
Q21.4	Aortopulmonary septal defect
Q21.8	Other congenital malformations of cardiac septa
Q21.9	Congenital malformation of cardiac septum, unspecified
Q22	Congenital malformations of pulmonary and tricuspid valves
Q22.0	Pulmonary valve atresia
Q22.1	Congenital pulmonary valve stenosis
Q22.2	Congenital pulmonary valve insufficiency
Q22.3	Other congenital malformations of pulmonary valve
Q22.4	Congenital tricuspid stenosis
Q22.5	Ebstein anomaly
Q22.6	Hypoplastic right heart syndrome
Q22.8	Other congenital malformations of tricuspid valve
Q22.9	Congenital malformation of tricuspid valve, unspecified
Q23	Congenital malformations of aortic and mitral valves
Q23.0	Congenital stenosis of aortic valve
Q23.1	Congenital insufficiency of aortic valve
Q23.2	Congenital mitral stenosis
Q23.3	Congenital mitral insufficiency
Q23.4	Hypoplastic left heart syndrome
Q23.8	Other congenital malformations of aortic and mitral valves
Q23.9	Congenital malformation of aortic and mitral valves, unspecified
Q24	Other congenital malformations of heart
Q24.0	Dextrocardia
Q24.1	Laevocardia
Q24.2	Cor triatriatum
Q24.3	Pulmonary infundibular stenosis
Q24.4	Congenital subaortic stenosis

Q24.5	Malformation of coronary vessels
Q24.6	Congenital heart block
Q24.8	Other specified congenital malformations of heart
Q24.9	Congenital malformation of heart, unspecified
Q25	Congenital malformations of great arteries
Q25.0	Patent ductus arteriosus
Q25.1	Coarctation of aorta
Q25.2	Atresia of aorta
Q25.3	Stenosis of aorta
Q25.4	Other congenital malformations of aorta
Q25.5	Atresia of pulmonary artery
Q25.6	Stenosis of pulmonary artery
Q25.7	Other congenital malformations of pulmonary artery
Q25.8	Other congenital malformations of great arteries
Q25.9	Congenital malformation of great arteries, unspecified
Q26	Congenital malformations of great veins
Q26.0	Congenital stenosis of vena cava
Q26.1	Persistent left superior vena cava
Q26.2	Total anomalous pulmonary venous connection
Q26.3	Partial anomalous pulmonary venous connection
Q26.4	Anomalous pulmonary venous connection, unspecified
Q26.5	Anomalous portal venous connection
Q26.6	Portal vein-hepatic artery fistula
Q26.8	Other congenital malformations of great veins
Q26.9	Congenital malformation of great vein, unspecified
Q28.8	Other specified congenital malformations of circulatory system
Q28.9	Congenital malformation of circulatory system, unspecified
Q87.4	Marfan syndrome
Q89.3	Situs inversus
ICD-10 acquired heart disease code	Description
I33	Acute and subacute endocarditis
I330	Acute and subacute infective endocarditis
I339	Acute and subacute endocarditis, unspecified
I34	Nonrheumatic mitral valve disorders
I340	Nonrheumatic mitral (valve) insufficiency
I341	Nonrheumatic mitral (valve) prolapse
I342	Nonrheumatic mitral (valve) stenosis
I348	Other nonrheumatic mitral valve disorders
I349	Nonrheumatic mitral valve disorder, unspecified
I35	Nonrheumatic aortic valve disorders
I350	Nonrheumatic aortic (valve) stenosis
I351	Nonrheumatic aortic (valve) insufficiency
I352	Nonrheumatic aortic (valve) stenosis with insufficiency
I358	Other nonrheumatic aortic valve disorders
I359	Nonrheumatic aortic valve disorder, unspecified
I36	Nonrheumatic tricuspid valve disorders

I360	Nonrheumatic tricuspid (valve) stenosis
I361	Nonrheumatic tricuspid (valve) insufficiency
I362	Nonrheumatic tricuspid (valve) stenosis with insufficiency
I368	Other nonrheumatic tricuspid valve disorders
I369	Nonrheumatic tricuspid valve disorder, unspecified
I37	Pulmonary valve disorders
I370	Nonrheumatic pulmonary valve stenosis
I371	Nonrheumatic pulmonary valve insufficiency
I372	Nonrheumatic pulmonary valve stenosis with insufficiency
I378	Other nonrheumatic pulmonary valve disorders
I379	Nonrheumatic pulmonary valve disorder, unspecified
I38	Endocarditis, valve unspecified
I39	Endocarditis and heart valve disorders in diseases classified elsewhere
I390	Mitral valve disorders in diseases classified elsewhere
I391	Aortic valve disorders in diseases classified elsewhere
I392	Tricuspid valve disorders in diseases classified elsewhere
I393	Pulmonary valve disorders in diseases classified elsewhere
I394	Multiple valve disorders in diseases classified elsewhere
I398	Endocarditis, valve unspecified, in diseases classified elsewhere
I40	Acute myocarditis
I400	Infective myocarditis
I401	Isolated myocarditis
I408	Other acute myocarditis
I409	Acute myocarditis, unspecified
I41	Myocarditis in diseases classified elsewhere
I410	Myocarditis in bacterial diseases classified elsewhere
I411	Myocarditis in viral diseases classified elsewhere
I412	Myocarditis in other infectious and parasitic diseases classified elsewhere
I418	Myocarditis in other diseases classified elsewhere
I42	Cardiomyopathy
I420	Dilated cardiomyopathy
I421	Obstructive hypertrophic cardiomyopathy
I422	Other hypertrophic cardiomyopathy
I423	Endomyocardial (eosinophilic) disease
I424	Endocardial fibroelastosis
I425	Other restrictive cardiomyopathy
I426	Alcoholic cardiomyopathy
I427	Cardiomyopathy due to drug and external agent
I428	Other cardiomyopathies
I429	Cardiomyopathy, unspecified
I43	Cardiomyopathy in diseases classified elsewhere
I430	Cardiomyopathy in infectious and parasitic diseases classified elsewhere
I431	Cardiomyopathy in metabolic diseases
I432	Cardiomyopathy in nutritional diseases
I438	Cardiomyopathy in other diseases classified elsewhere
I44	Atrioventricular and left bundle-branch block

I440	Atrioventricular block, first degree
I441	Atrioventricular block, second degree
I442	Atrioventricular block, complete
I443	Other atrioventricular block
I444	Left anterior fascicular block
I445	Left posterior fascicular block
I446	Other fascicular block
I447	Left bundle-branch block, unspecified
I45	Other conduction disorders
I450	Right fascicular block
I451	Other right bundle-branch block
I452	Bifascicular block
I453	Trifascicular block
I454	Nonspecific intraventricular block
I455	Other specified heart block
I456	Pre-excitation syndrome
I458	Other specified conduction disorders
I459	Conduction disorder, unspecified
I46	Cardiac arrest
I4.0	Cardiac arrest with successful resuscitation
I461	Sudden cardiac death, so described
I462	Cardiac arrest due to underlying cardiac condition
I468	Cardiac arrest due to other underlying condition
I469	Cardiac arrest, cause unspecified
I47	Paroxysmal tachycardia
I470	Re-entry ventricular arrhythmia
I471	Supraventricular tachycardia
I472	Ventricular tachycardia
I479	Paroxysmal tachycardia, unspecified
I48	Atrial fibrillation and flutter
I480	Paroxysmal atrial fibrillation
I481	Persistent atrial fibrillation
I482	Chronic atrial fibrillation
I483	Typical atrial flutter
I484	Atypical atrial flutter
I489	Atrial fibrillation and atrial flutter, unspecified
I49	Other cardiac arrhythmias
I490	Ventricular fibrillation and flutter
I491	Atrial premature depolarization
I492	Junctional premature depolarization
I493	Ventricular premature depolarization
I494	Other and unspecified premature depolarization
I495	Sick sinus syndrome
I498	Other specified cardiac arrhythmias
I499	Cardiac arrhythmia, unspecified
I50	Heart failure

I500	Congestive heart failure
I501	Left ventricular failure
I509	Heart failure, unspecified

Table S11 Total number of NCHDA records and number and percentage of those with a valid NHS number, broken down by country of residence derived from postcode (by NICOR).

Country of residence from patient postcode	Total NCHDA records	Valid NHS number (number of records)	Valid NHS number (percentage of records)
England	129,952	128,351	98.8%
Wales	6,514	6,457	99.1%
Crown Dependencies	531	342	64.4%
Scotland	681	241	35.4%
Northern Ireland	1,085	80	7.4%
Overseas	1,981	144	7.3%
Missing or invalid postcode	3,118	642	20.6%
Total	143,862	136,257	94.7%

Table S12 Quality of NHS numbers in each of the data sets (across all records before linkage): yearly total number of records and percentage of records with valid NHS numbers.

Financial Year	NCHDA n (% valid)	PICANet n (% valid)	ICNARC-CMP n (% valid)	HES Inpatient n (% valid)	HES Outpatient n (% valid)	HES A&E n (% valid)
1998				11,983,893 (74.3%)		
1999				12,196,270 (80.3%)		
2000	6,422 (85.1%)			12,264,676 (83.2%)		
2001	6,170 (92.5%)			12,337,724 (86.5%)		
2002	6,102 (93.7%)	2,427 (80.2%)		12,712,153 (90.5%)		
2003	7,446 (93.3%)	8,171 (76.9%)		13,295,166 (93.6%)	51,427,003 (93.8%)	
2004	6,936 (94.2%)	8,846 (75.7%)		13,706,450 (95.4%)	54,420,813 (95.6%)	
2005	7,720 (94.4%)	9,699 (75.9%)		14,423,506 (95.7%)	60,608,403 (96.5%)	
2006	8,122 (94.9%)	10,288 (84.4%)	81,752 (4.5%)	14,784,581 (96.4%)	63,217,226 (97.0%)	
2007	7,972 (95.4%)	11,146 (89.9%)	93,669 (56.7%)	15,359,062 (96.7%)	66,649,484 (97.8%)	12,318,051 (85.4%)
2008	8,324 (95.3%)	11,742 (90.6%)	101,926 (82.8%)	16,232,579 (97.1%)	74,853,493 (98.1%)	13,794,072 (88.8%)
2009	8,726 (96.2%)	12,646 (91.6%)	114,519 (90.4%)	16,806,196 (97.8%)	84,198,458 (98.2%)	15,569,736 (90.1%)
2010	8,969 (96.4%)	13,236 (93.1%)	135,880 (93.3%)	17,269,882 (98.2%)	87,998,505 (98.7%)	16,244,934 (92.0%)
2011	9,107 (96.9%)	13,390 (94.5%)	156,181 (95.0%)	17,465,425 (98.5%)	90,956,844 (98.8%)	17,619,708 (93.6%)
2012	8,994 (95.9%)	14,307 (94.6%)	160,737 (95.8%)	17,715,046 (98.7%)	94,091,748 (99.0%)	18,328,896 (95.1%)
2013	9,582 (95.3%)	14,551 (95.1%)	170,073 (96.1%)	18,163,101 (98.7%)	101,844,824 (99.0%)	18,517,381 (96.0%)
2014	9,641 (95.4%)	15,659 (94.8%)	191,585 (96.0%)	18,731,987 (98.8%)	107,188,423 (99.2%)	19,556,781 (95.2%)
2015	11,472 (94.8%)	16,898 (94.9%)	206,383 (96.1%)	19,239,608 (98.8%)	113,298,661 (99.2%)	20,457,805 (95.9%)
2016	12,157 (95.9%)	16,785 (96.6%)	217,496 (96.4%)	19,726,907 (98.5%)	118,578,912 (99.4%)	20,886,411 (96.9%)
2017			223,367 (96.7%)	20,030,870 (98.3%)	119,378,895 (99.4%)	21,278,504 (97.1%)
All years	143,862 (94.7%)	179,791 (90.5%)	1,853,568 (88.7%)	314,445,082 (93.8%)	1,288,711,692 (98.0%)	194,572,279 (93.3%)

Note: We do not know the quality of identifiers in ONS mortality data, which we obtained linked to HES data.

Table S13 Number of linked records in each data set before quality assurance, by estimated financial year

Financial Year	NCHDA	PICANet	ICNAR C-CMP	HES Inpatient	HES Outpatient	HES A&E	Total
1998	0	0	0	16,498	0	0	16,498
1999	0	0	0	19,902	0	0	19,902
2000	6,421	15	2	29,235	0	0	35,673
2001	6,161	11	1	33,390	0	0	39,563
2002	6,137	952	0	37,128	0	0	44,217
2003	7,402	3,226	0	43,106	132,710	0	186,444
2004	6,968	3,464	0	45,657	150,065	0	206,154
2005	7,684	3,828	0	50,436	177,020	0	238,968
2006	8,152	4,052	6	52,256	196,331	0	260,797
2007	7,984	4,136	154	56,918	224,342	23,352	316,886
2008	8,294	4,275	215	60,251	255,702	27,597	356,334
2009	8,719	4,748	273	65,634	294,368	32,876	406,618
2010	8,987	4,891	388	69,485	323,853	35,989	443,593
2011	9,102	5,103	407	70,851	348,802	38,968	473,233
2012	9,013	5,176	411	71,279	370,113	41,745	497,737
2013	9,593	5,435	473	72,077	408,561	42,959	539,098
2014	9,639	5,435	447	73,027	442,349	45,018	575,915
2015	11,492	5,546	629	76,245	470,121	47,341	611,374
2016	12,114	5,504	686	73,112	478,591	47,060	617,067
2017	0	0	572	52,074	426,352	43,604	522,602
All years	143,862	65,797	4,664	1,068,561	4,699,280	426,509	6,408,673

Note: financial years (running from April to March) were estimated using the ages at events and the estimated date of birth (we took day 15th of the known month of birth as date of birth).