How successful is transfer from paediatric to adult services for patients with congenital heart disease?

SUPPLEMENTARY MATERIAL

1. Patient Selection

As described in the main manuscript Figure 1, we selected patients born between 1 April 1987 and 31 March 2000, having a CHD procedure (excluding heart transplant) as children in public hospitals from England, known to be alive at age 16, and with Hospital Episode Statistic (HES) data successfully linked to their National CHD Audit (NCHDA) records in the LAUNCHES dataset (LAUNCHES stands for "Linking Audit and National datasets in Congenital Heart Services for Quality Improvement"). Life status was ascertained using ONS mortality registry; when linkage to ONS was not available, their clinical records were used. Patients were required to have had a CHD procedure as children in NCHDA, the UK national registry of CHD procedures. Heart transplants were excluded from the analysis because care in adulthood post-transplant remains with the transplanting centre. Most of the restrictions were posed by the need to have outpatient and inpatient data at ages 16-20 for the cohorts of analysis, as such attendance data was only available from HES data for public hospitals in England from 1 April 2003 onwards (Figure S1). The main known reasons for non-linkage of NCHDA to HES were: missing NHS number; residence not recorded or outside England; and/or record from before 2003 when data quality was poorer.

2. Identifying Transfer to ACHD Services

Successful transfer to specialist ACHD services was assigned when the patient was seen in cardiology out-patients or admitted as a cardiology in-patient in a recognised specialist ACHD centre, or one of its affiliated outreach centres. This outcome assignation required the identification of cardiac contacts (at inpatient or outpatient services) and the identification of ACHD hospitals. We required the transfers to take place at ages 16 to end of 21 (full cohort) or to end of age 19 (severe and moderately complex patients).

Cardiac contacts

1. Outpatient Cardiac Appointments were identified in HES data using the Treatment Speciality (TRETSPEF) field from HES OP (before 2004/05, TRETSPEF contained the consultant speciality instead of treatment speciality).
   1.1. Only the treatment specialities in Table S1 were considered indicators of ACHD appointments.
   1.2. Patient attendance to outpatient appointments was recorded in HES by all centres. Only cardiac appointments were used in the analyses as evidence of patient contact with CHD services.
2. Inpatient Cardiac Admissions were identified in HES data using the following Healthcare Resource Group (HRG) codes, noting different structural HRG versions during the period of study:
   2.1. E-codes (Cardiac surgery and primary cardiac conditions);
   2.2. HRG3 code : P25 (Cardiac conditions);
   2.3. HRG4 codes: PA22Z (Chest pain), PA23A and PA23B (Cardiac conditions with/without complications and comorbidities (CC)), and PA24Z (Arrhythmia or conduction disorders).
   2.4. HRG4+ codes: PE23A-PE23F (Paediatric cardiac conditions, with different CC scores), PE24A-PE24C (Paediatric arrhythmia or conduction disorders, with different CC scores), and PE62A-PE62C (Paediatric syncope and collapse, with different CC scores).
3. All NCHDA reported procedures were considered to be cardiac contacts.

ACHD hospital levels

1. Hospitals in HES data were classified as Adult CHD Level 1, Level 2, Level3 or outreach according National Service Standards and Specifications (11) and are found in Table S2. The purely paediatric hospitals (horizontal model) were identified using Table S3.
2. Hospitals in NCHDA were classified as ACHD hospitals (some admitting children as well) except for 3 purely paediatric level 1 hospitals (Alder Hey Hospital, Birmingham Children's Hospital, and Great Ormond Street Hospital for Children).

3. Patient Characteristics at Baseline

1. Birth Cohort was assigned using the LAUNCHES revised patient level date of birth (both year and month of birth were available).
2. Sex was assigned as the mode of the NCHDA record level "gender" field over all patient records (not just the records before age 16). Where it was missing the mode over all patient records of the HES record level "sex" field was used.
3. Ethnicity was assigned in a similar way, where non-white groups were merged together.
4. Area Deprivation. We use the postcode-derived quintile of Index of multiple deprivation (QIMD) from the last HES record of the patient before age 16. The first two quintiles (Q1, Q2) were assigned as Deprived Area, and the rest (Q3,4,5) were assigned non-deprived. https://www.gov.uk/government/collections/english-indices-of-deprivation
5. Treatment in Purely Paediatric Level 1 Hospital as child was identified if the patient had had a cardiac contact (definition in previous section) before age 16 in any of the paediatric-only CHD Level 1 hospitals (definition in previous section).
6. Complexity Classification. A complexity classification (mild, moderate, severe) in accordance with current ESC guidelines was assigned using both NCHDA diagnostic and procedural categories and HES ICD-10 diagnostic codes. We first assigned a complexity classification to each NCHDA primary diagnosis category (Table S4), HES ICD-10 diagnosis codes (Table S5), and NCHDA specific procedure category (Table S6). Then, for each patient the most severe complexity classification over their records before age 16 was assigned as patient complexity classification at baseline for all analyses.

4. Statistical Analysis

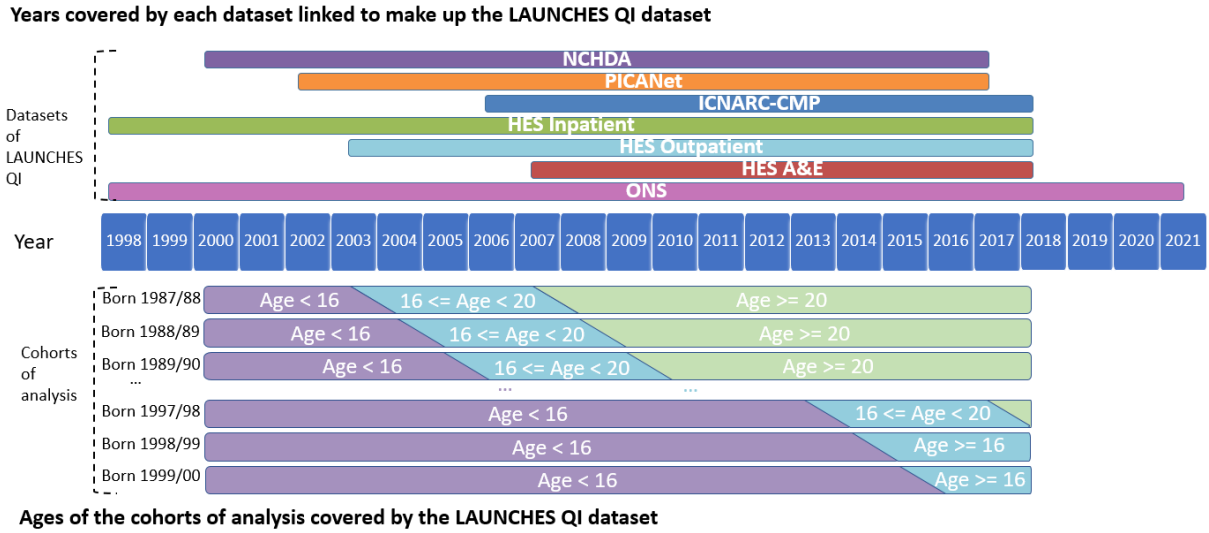
For some patients (depending on their birth cohort as per Figure S1) the data did not cover the whole period of follow-up ages, 16 to end of 19th year or end of 21st year, and right-censored outcomes and time-to-event ages were used (rather than deleting the censored cohorts). Patients' death without transfer was not considered a (non-informative) censoring event, but a competing risk outcome that prevents transfer to ACHD services and as such it needs to be reported separately. The main paper provides tables with outcome and censoring numbers at endpoint. Competing Risk Analysis tools were used such as Conditional Probability Functions (CPFs) over the period of ages, estimating at any time point the probability of patients being transferred to ACHD services conditional on being alive. Alternative pairs of complementary Conditional Incidence Functions for the two competing outcomes (transfer versus death before transfer) were tested, but the differences in the Cumulative Incidence Function (CIF) of death were not significant (small numbers) and interpreting the complementary CIF of transfer was not possible ignoring the CIFs of death; we opted to report deaths separately and to show CPF probabilities of transfer conditional on being alive. Average (with 95% CI) CPF curves were shown in figures 2, 3, and S2; average (with 95% CI) CPF values were tabulated at end of follow-up (tables 2 and 3).

We estimated the odds ratios of transfer at end point using a multivariable logistic regression model (Table 4). The considered covariates are reported above as "patient characteristics at baseline". All variables that were significant in single variable logistic regressions at end point were included in the multivariable model. The sample used for the logistic regression analyses were moderate and severe complexity patients that were alive and with data by their 20th birthday (born before 1998/99). We clustered the standard errors by last centre before age 16 to account for differences in transfer assignment by centre (further than the care model tested as risk factor). Centres before age 16 with small numbers were excluded; in practice this resulted in excluding two patients, the final sample size for the logistic regression analysis being N=4,036 (reported in Note to Table 4).

For the severe and moderate complexity patients alive and with data at age 20, we further looked at their survival probability (Kaplan Meier estimate of risk of death in Figure 4A) and their probability of getting a congenital cardiac procedure as recorded in the NCHDA audit (CPF of the probability of NCHDA procedure conditional on being alive in Figure 4B).

FIGURES AND TABLES

Figure S1. Years covered by the LAUNCHES dataset and age overlap with the cohorts of analysis.



Notes: Calendar years are displayed at the top of this figure, while the data were obtained by financial years, which run from 1st April to 31st March.
NCHDA = National Congenital Heart Disease Audit PICANet = Paediatric Intensive Care Audit Network ICNARC-CMP = Intensive Care National Audit & Research Centre Case Mix Programme HES = Hospital Episode Statistics A&E = Accident and Emergency ONS = Office for National Statistics (mortality)

Table S1. Treatment specialities (code and description) considered as indicative of cardiac contacts in Hospital Episodes Statistics outpatient records.

Treatment Speciality Code	Treatment Speciality Description
170	Cardiothoracic Surgery (Where There Are No Separate Services for Cardiac and Thoracic Surgery)
172	Cardiac Surgery
174	Cardiothoracic Transplantation (Recognised Specialist Services Only - Includes 'Outreach' Facilities)

221	Paediatric Cardiac Surgery (From 2006-07)
320	Cardiology
321	Paediatric Cardiology
331	Congenital Heart Disease Service (From April 2013)

Table S2. Classification of hospital providers in Hospital Episode Statistics data by adult congenital heart disease level. It includes vertical model centres.

Provider Code	Provider Description	ACHD Level
RNJ	BARTS AND THE LONDON NHS TRUST	Level 1
R1H	BARTS HEALTH NHS TRUST	Level 1
RW3	CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	Level 1
RJ1	GUY'S AND ST THOMAS' NHS FOUNDATION TRUST (including Evelina London Children's Hospital)	Level 1 (also paed)
RR8	LEEDS TEACHING HOSPITALS NHS TRUST	Level 1 (also paed)
RBQ	LIVERPOOL HEART AND CHEST HOSPITAL NHS FOUNDATION TRUST	Level 1
RT3	ROYAL BROMPTON & HAREFIELD NHS FOUNDATION TRUST	Level 1 (also paed)
RQ6	ROYAL LIVERPOOL AND BROADGREEN UNIVERSITY HOSPITALS NHS TRUST	Level 1
RTD	THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	Level 1
RRV	UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST	Level 1
RHM	UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	Level 1 (also paed)
RRK	UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	Level 1
RA7	UNIVERSITY HOSPITALS BRISTOL AND WESTON NHS FOUNDATION TRUST (including Bristol Royal Children's Hospital)	Level 1 (also paed)
RWE	UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	Level 1 (also paed)
R1H	BARTS HEALTH NHS TRUST	Level 1
RBQ	LIVERPOOL HEART AND CHEST HOSPITAL NHS FOUNDATION TRUST	Level 1
RXH	BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST	Level 2
R0A	MANCHESTER UNIVERSITY NHS FOUNDATION TRUST	Level 2
RM1	NORFOLK AND NORWICH UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	Level 2
RTH	OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	Level 2
RGM	ROYAL PAPWORTH HOSPITAL NHS FOUNDATION TRUST	Level 2
RXL	BLACKPOOL TEACHING HOSPITALS NHS FOUNDATION TRUST	Level 3
RJF	BURTON HOSPITALS NHS FOUNDATION TRUST	Level 3
RTE	GLOUCESTERSHIRE HOSPITALS NHS FOUNDATION TRUST	Level 3
RN3	GREAT WESTERN HOSPITALS NHS FOUNDATION TRUST	Level 3
RWA	HULL UNIVERSITY TEACHING HOSPITALS NHS TRUST	Level 3
RNQ	KETTERING GENERAL HOSPITAL NHS FOUNDATION TRUST	Level 3
RD8	MILTON KEYNES UNIVERSITY HOSPITAL NHS FOUNDATION TRUST	Level 3
RGN	NORTH WEST ANGLIA NHS FOUNDATION TRUST	Level 3
RNS	NORTHAMPTON GENERAL HOSPITAL NHS TRUST	Level 3
RBZ	NORTHERN DEVON HEALTHCARE NHS TRUST	Level 3
RX1	NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST	Level 3

RHW	ROYAL BERKSHIRE NHS FOUNDATION TRUST	Level 3
REF	ROYAL CORNWALL HOSPITALS NHS TRUST	Level 3
RH8	ROYAL DEVON AND EXETER NHS FOUNDATION TRUST	Level 3
RD1	ROYAL UNITED HOSPITALS BATH NHS FOUNDATION TRUST	Level 3
RCU	SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST	Level 3
RHQ	SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	Level 3
RK5	SHERWOOD FOREST HOSPITALS NHS FOUNDATION TRUST	Level 3
RXW	SHREWSBURY AND TELFORD HOSPITAL NHS TRUST	Level 3
RTR	SOUTH TEES HOSPITALS NHS FOUNDATION TRUST	Level 3
RJC	SOUTH WARWICKSHIRE NHS FOUNDATION TRUST	Level 3
RBA	TAUNTON AND SOMERSET NHS FOUNDATION TRUST	Level 3
RL4	THE ROYAL WOLVERHAMPTON NHS TRUST	Level 3
RA9	TORBAY AND SOUTH DEVON NHS FOUNDATION TRUST	Level 3
RWD	UNITED LINCOLNSHIRE HOSPITALS NHS TRUST	Level 3
RM2	UNIVERSITY HOSPITAL OF SOUTH MANCHESTER NHS FOUNDATION TRUST	Level 3
RKB	UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST	Level 3
RTG	UNIVERSITY HOSPITALS OF DERBY AND BURTON NHS FOUNDATION TRUST	Level 3
RJE	UNIVERSITY HOSPITALS OF NORTH MIDLANDS NHS TRUST	Level 3
RK9	UNIVERSITY HOSPITALS PLYMOUTH NHS TRUST	Level 3
RWP	WORCESTERSHIRE ACUTE HOSPITALS NHS TRUST	Level 3
RA4	YEOVIL DISTRICT HOSPITAL NHS FOUNDATION TRUST	Level 3
RTK	ASHFORD AND ST PETER'S HOSPITALS NHS FOUNDATION TRUST	Outreach
RDD	BASILDON AND THURROCK UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	Outreach
RC9	BEDFORDSHIRE HOSPITALS NHS FOUNDATION TRUST	Outreach
RDE	EAST SUFFOLK AND NORTH ESSEX NHS FOUNDATION TRUST	Outreach
RXC	EAST SUSSEX HEALTHCARE NHS TRUST	Outreach
RGQ	IPSWICH HOSPITAL NHS TRUST	Outreach
RJ2	LEWISHAM AND GREENWICH NHS TRUST	Outreach
RWF	MAIDSTONE AND TUNBRIDGE WELLS NHS TRUST	Outreach
RPA	MEDWAY NHS FOUNDATION TRUST	Outreach
RD3	POOLE HOSPITAL NHS FOUNDATION TRUST	Outreach
RHU	PORTSMOUTH HOSPITALS UNIVERSITY NATIONAL HEALTH SERVICE TRUST	Outreach
RA2	ROYAL SURREY COUNTY HOSPITAL NHS FOUNDATION TRUST	Outreach
RPR	ROYAL WEST SUSSEX NHS TRUST	Outreach
RNZ	SALISBURY NHS FOUNDATION TRUST	Outreach
RTP	SURREY AND SUSSEX HEALTHCARE NHS TRUST	Outreach
RCX	THE QUEEN ELIZABETH HOSPITAL, KING'S LYNN, NHS FOUNDATION TRUST	Outreach
RYR	WESTERN SUSSEX HOSPITALS NHS FOUNDATION TRUST	Outreach

Table S3. Classification of hospital providers in Hospital Episode Statistics data by paediatric congenital heart disease level. Only horizontal model centres included.

Provider Code	**Provider Description**	**Paediatric CHD Level**

RBS	ALDER HEY CHILDREN'S NHS FOUNDATION TRUST	Level 1
RQ3	BIRMINGHAM WOMEN'S AND CHILDREN'S NHS FOUNDATION TRUST	Level 1
RP4	GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST	Level 1
RCU	SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST	Level 3

Table S4. Complexity classification assigned to each Primary Diagnosis category from the NCHDA records in the LAUNCHES dataset.

Overall NCHDA diagnosis category	**ESC Complexity**
1: Hypoplastic left heart syndrome	severe
2: Functionally UVH	severe
3: Common arterial trunk (truncus arteriosus)	severe
4: Transposition of great arteries & ventricular septal defect/Transposition-type double outlet right ventricle	severe
5: Interrupted Aortic Arch	severe
6: Transposition of great arteries & intact ventricular septum	moderate
7: Pulmonary atresia & intact ventricular septum	severe
8: Pulmonary atresia & ventricular septal defect	severe
9: Miscellaneous primary congenital disease	ambiguous
10: Atrioventricular septal defect	moderate
11: Tetralogy of Fallot /Fallot-type double outlet right ventricle	moderate
12: Aortic valve stenosis (isolated)	moderate
13: Tricuspid valve anomaly including Ebstein anomaly	moderate
14: Mitral valvar abnormality	moderate
15: Total anomalous pulmonary venous connection	moderate
16: Aortic arch obstruction +/- ventricular septal defect +/- atrial septal defect	moderate
17: Pulmonary stenosis	moderate
18: Subaortic stenosis (isolated)	moderate
19: Aortic regurgitation	moderate
20: Ventricular septal defect	mild
21: Atrial septal defect	mild
22: Patent arterial duct (PDA)	mild
23: Acquired paediatric heart disease	ambiguous
24: Arrhythmia requiring procedure	mild
25: Misc congenital terms	ambiguous
Missing diagnosis	ambiguous

Table S5. Complexity classification assigned to each ICD-10 Diagnosis code from the HES records in the LAUNCHES dataset.

ICD-10 Code	**ICD-10 Description**	**ESC Complexity**

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

Q24.8	Other specified congenital malformations of heart	ambiguous
Q24.9	Congenital malformation of heart, unspecified	ambiguous
Q25	Congenital malformations of great arteries	ambiguous
Q25.0	Patent ductus arteriosus	mild
Q25.1	Coarctation of aorta	moderate
Q25.2	Atresia of aorta	severe
Q25.3	Stenosis of aorta	moderate
Q25.4	Other congenital malformations of aorta	ambiguous
Q25.5	Atresia of pulmonary artery	severe
Q25.6	Stenosis of pulmonary artery	moderate
Q25.7	Other congenital malformations of pulmonary artery	ambiguous
Q25.8	Other congenital malformations of great arteries	ambiguous
Q25.9	Congenital malformation of great arteries, unspecified	ambiguous
Q26	Congenital malformations of great veins	ambiguous
Q26.0	Congenital stenosis of vena cava	ambiguous
Q26.1	Persistent left superior vena cava	ambiguous
Q26.2	Total anomalous pulmonary venous connection	moderate
Q26.3	Partial anomalous pulmonary venous connection	moderate
Q26.4	Anomalous pulmonary venous connection, unspecified	moderate
Q26.5	Anomalous portal venous connection	ambiguous
Q26.6	Portal vein-hepatic artery fistula	ambiguous
Q26.8	Other congenital malformations of great veins	ambiguous
Q26.9	Congenital malformation of great vein, unspecified	ambiguous
Q87.4	Marfan syndrome	moderate
Q89.3	Situs inversus	ambiguous
Z95.2	Presence of prosthetic heart valve	moderate

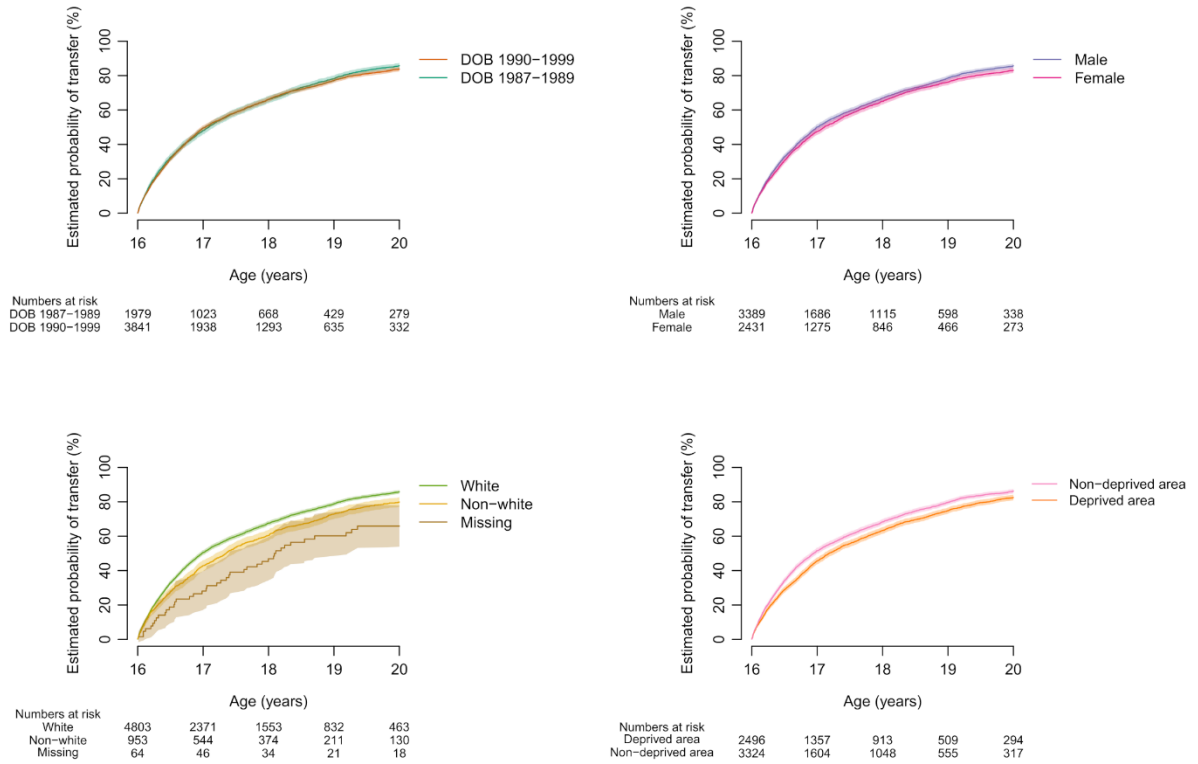
Table S6. Complexity classification assigned to each Specific Procedure category from the NCHDA records in the LAUNCHES dataset.

NCHDA specific procedure category	**ESC Complexity**
01: Norwood procedure	severe
02: Heart transplant	exclusion
03: Lung transplant (includes heart and lung transplant)	exclusion
05: Common arterial trunk (truncus arteriosus) repair	severe
06: Double Switch or Rastelli-Senning repair of ccTGA a	severe
07: Double Switch or Rastelli-Senning repair of ccTGA b	severe
08: Senning or Mustard procedure (atrial switch)	ambiguous
09: Rastelli or REV procedure	severe
10: Complex procedure for transposed great arteries	severe
12: Arterial switch and ventricular septal defect (VSD) repair	severe
13: Arterial switch	moderate
15: Totally anomalous pulmonary venous connection (TAPVC) repair	moderate
16: Fontan or Total Cavopulmonary Connection (TCPC)	severe
17: Glenn (Cavopulmonary (CP) shunt)	severe

19: Atrioventricular septal defect (AVSD) & Tetralogy of Fallot repair	moderate
20: Complete atrioventricular septal defect (AVSD) repair	moderate
21: Partial atrioventricular septal defect (AVSD) repair	moderate
22: Mitral_valve_replacement	moderate
23: Ross-Konno procedure a	moderate
24: Ross-Konno procedure b	moderate
25: Ross procedure (aortic valve-root replacement with pulmonary autograph)	moderate
26: Aortic root replacement (non-Ross)	moderate
27: Aortic valve replacement (non-Ross)	moderate
28: Tricuspid valve replacement	moderate
29: Pulmonary valve replacement	moderate
30: Mitral valve repair	moderate
31: Aortic valve repair	moderate
32: Tricuspid valve repair	moderate
33: Pulmonary atresia & ventricular septal defect (VSD) repair	severe
34: Systemic-to-pulmonary collateral artery (MAPCA) unifocalisation procedure	severe
35: Tetralogy of Fallot with absent pulmonary valve repair	moderate
36: Tetralogy of Fallot and Fallot-type double outlet right ventricle repair	moderate
37: Right ventricle to pulmonary arterial conduit	moderate
38: Ventricular septal defect and right ventricular outflow tract obstruction repair	moderate
39: Supravalvar aortic stenosis repair	moderate
40: Subaortic stenosis repair	moderate
42: Anomalous coronary artery repair	moderate
43: Cor triatriatum (divided left atrium) repair	moderate
44: Isolated pulmonary trunk band (PA band)	ambiguous
45: Systemic-to-pulmonary arterial shunt procedure (includes Blalock-Taussig & central shunts)	severe
46: Interrupted aortic arch repair	severe
47: Isolated coarctation/hypoplasia of aorta repair	moderate
48: Pulmonary vein stenosis repair	moderate
49: Replacement of cardiac conduit	ambiguous
50: Closure of multiple ventricular septal defects (VSD)	mild
51: Ventricular septal defect (VSD) closure - surgical	mild
52: Sinus venosus atrial septal defect (ASD) closure and partially anomalous pulmonary venous connection (PAPVC) repair	mild
53: Vascular ring repair	mild
54: Atrial septal defect (ASD) closure - surgical	mild
55: Patent arterial duct (PDA) closure - surgical	mild
56: Arrhythmia-related surgical procedure	moderate
57: Permanent epicardial pacemaker system placement	moderate
58: Stent placement in arterial duct (PDA)	severe
59: pulmonary valve replacement: transluminal	moderate
60: Stent placement in right ventricular outflow tract (RVOT)	moderate

61: Transluminal pulmonary valve perforation & dilation	severe
62: Blade atrial septostomy	ambiguous
63: Balloon atrial septostomy by pull back	moderate
64: Balloon dilation and/or stenting of pulmonary vein	severe
65: Stent placement at site of aortic coarctation	moderate
66: Balloon dilation of native aortic coarctation-hypoplasia	moderate
67: Balloon dilation of aortic re-coarctation	moderate
68: Balloon dilation of aortic valve	moderate
69: Balloon dilation of pulmonary valve	moderate
70: Transluminal ventricular septal defect (VSD) closure	mild
71: Transluminal patent foramen ovale (PFO) closure	mild
72: Transluminal atrial septal defect (ASD) closure	mild
73: Transluminal patent arterial duct (PDA) closure	mild
74: Stent placement in pulmonary artery	moderate
75:pa ballooning	moderate
76: Transluminal systemic-to-pulmonary collateral artery (MAPCA) procedure	ambiguous
77: Stent or balloon dilation of cardiac conduit	moderate
78: Stent redilation	moderate
79: Transluminal ablation procedure for arrhythmia	mild
80: Implantable cardioverter & defibrillator (ICD) implantation	moderate
82: Biventricular implantable cardioverter & defibrillator (ICD) implantation or pacemaker system placement	moderate
83: Pacemaker system placement or generator replacement - surgical	moderate
84: Pacemaker lead procedure	moderate
85: Miscellaneous electrophysiology (EP) procedures	mild
86: Diagnostic electrophysiological study (EPS)	mild
87: Catheter diagnostic	mild
99: Unallocated	ambiguous

Figure S2. Severe and Moderate patient group estimated probability of transfer if alive by era, sex, ethnicity, and deprivation over the follow-up period between 16th and 20th birthdays. The estimated probabilities conditional on survival of patients take into account the mortality and censoring of patients.



Notes. The CPFs by birth cohort were not significantly different (Pepe-Mori test p-value 0.575). The male vs female CPFs was narrowly significantly different (Pepe-Mori test p-value 0.047). The ethnicity CPFs were significantly different pairwise (Pepe-Mori test p-values <0.001 for white against non-white or missing, and p-value 0.014 for non-white compared to missing. The CPFs by are deprivation were significantly different (Pepe-Mori test p-value <0.001).