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Transfer of congenital heart patients from paediatric to adult services in England

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ABSTRACT

Objective This study assessed the transfer of patients from paediatric cardiac to adult congenital heart disease (ACHD) services in England and the factors impacting on this process.

Methods This retrospective cohort study used a population-based linked data set (LAUNCHES QI data set: 'Linking Audit and National datasets in Congenital Heart Services for Quality Improvement') including all patients born between 1987 and 2000, recorded as having a congenital heart disease (CHD) procedure in childhood. Hospital Episode Statistics data identified transfer from paediatric to ACHD services between the ages of 16 and 22 years.

Results Overall, 63.8% of a cohort of 10 298 patients transferred by their 22nd birthday. The estimated probability of transfer by age 22 was 96.5% (95% CI 95.3 to 97.7), 86.7% (95% CI 85.6 to 87.9) and 41.0% (95% CI 39.4 to 42.6) for severe, moderate and mild CHD, respectively. 166 patients (1.6%) died between 16 and 22 years; 42 of these (0.4%) died after age 16 but prior to transfer. Multivariable ORs in the moderate and severe CHD groups up to age 20 showed significantly lower likelihood of transfer among female patients (0.87, 95% CI 0.78 to 0.97), those with missing ethnicity data (0.31, 95% CI 0.18 to 0.52), those from deprived areas (0.84, 95% CI 0.72 to 0.98) and those with moderate (compared with severe) CHD (0.30, 95% CI 0.26 to 0.35). The odds of transfer were lower for the horizontal compared with the vertical care model (0.44, 95% CI 0.27 to 0.72). Patients who did not transfer had a lower probability of a further National Congenital Heart Disease Audit procedure between ages 20 and 30 compared with those who did transfer: 12.3% (95% CI 5.1 to 19.6) vs 32.5% (95% CI 28.7 to 36.3).

Conclusions Majority of patients with moderate or severe CHD in England transfer to adult services. Patients who do not transfer undergo fewer elective CHD procedures over the following decade.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Previous studies have reported high rates of loss to follow-up at the point of transfer to adult congenital heart disease (ACHD) services.
⇒ Gaps in care are associated with worse outcomes.

WHAT THIS STUDY ADDS

⇒ This study demonstrates that transfer from paediatric to ACHD services in England for patients with more complex congenital heart disease is highly effective, with a stepwise reduction in transfer rates in moderately complex and mildly complex patients.
⇒ The study demonstrates clear differences in practice between centres with a vertical and a horizontal model of delivering care.
⇒ Patients who do not transfer undergo fewer interventional or surgical procedures during the following decade.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The UK model of specialised service provision with ACHD services closely affiliated with paediatric cardiology centres facilitates transfer of moderately and severely complex patients.
⇒ Horizontal and vertical model centres clearly have different transfer policies, with more patients from horizontal models (stand-alone paediatric hospitals) transferring later and failing to ultimately transfer at all.
⇒ More work is required to understand the value of ongoing care in adulthood for patients with simple lesions.
⇒ Barriers to transfer for ethnic minorities and those from deprived areas should be further assessed and addressed.

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INTRODUCTION

Survival after paediatric cardiac surgery and catheter interventions for congenital heart disease (CHD) in the UK is excellent and the vast majority of children undergoing treatment for even complex anatomy now reach adulthood.[1 2] Because these patients are at increased risk of late cardiac complications, including arrhythmia, pulmonary hypertension, heart failure, endocarditis and premature death,[3–7] long-term follow-up in adult congenital heart disease (ACHD) services is recommended.[8] Patients lost to specialist ACHD follow-up have an increased risk of premature death and do not benefit from standard interventions designed to optimise cardiac function and longevity.[9 10]

Between the 1960s and 1980s paediatric cardiac surgery was provided in many small units across England, before becoming more concentrated in a smaller number of higher volume centres. Many of the current designated ACHD programmes have developed in conjunction with those centres, but until the late 1990s the relatively small number of

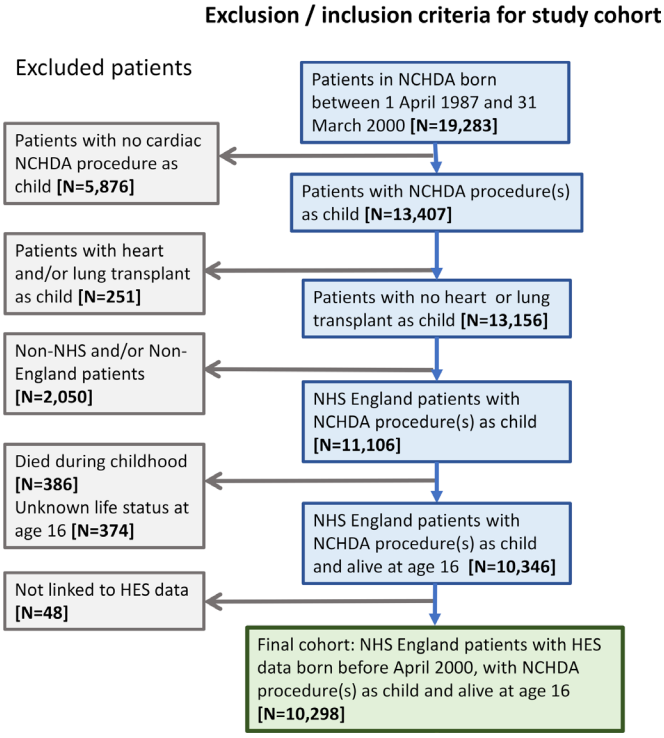

Figure 1 Inclusion and exclusion criteria. HES, Hospital Episode Statistics; NCHDA, National Congenital Heart Disease Audit; NHS, National Health Service.

patients with complex ACHD and the scarcity of expertise in ACHD meant that services were fragmented. Often patients were referred to general adult cardiology services, and as many as 30% of patients were lost to follow-up at the point of transfer.[11] A formal structure for healthcare services for patients with ACHD is now well established in the UK, supported by the publication of the National Service Standards and Specifications in 2016.[12] An entire section is dedicated to transition, including standards for a structured transition programme beginning at age 12, with transfer from paediatric to specialised ACHD care from age 16.

This study used the LAUNCHES QI ('Linking Audit and National datasets in Congenital Heart Services for Quality Improvement') data set[13] to examine the transfer of patients from paediatric to adult congenital heart services in England.

METHODS

Data set

Information on patients with CHD and their utilisation of healthcare services in England and Wales is not available in a single data set. Since April 2000, the main source of information on outcomes following therapeutic congenital cardiovascular procedures in the UK has been the mandatory National Congenital Heart Disease Audit (NCHDA).[14] As part of the LAUNCHES QI project, a combined data set for understanding patient journeys across care systems was built to explore variation across services and identify priorities for quality improvement.[13] The NCHDA was linked with national validated registries: 'PICANet' (Paediatric Intensive Care Audit Network) [15] and 'ICNARC-CMP' (Intensive Care National Audit and Research Centre-Case Mix Programme) [16]; death registrations from Office for National Statistics (ONS); and Hospital Episode Statistics (HES) for routine National Health Service data on hospital admissions, accident and emergency attendances, and outpatient appointments in England.[17] Using the LAUNCHES QI data set, this retrospective study examines transfer from paediatric services to ACHD services in a large cohort of patients and the factors affecting successful transfer.

Table 1 Patient characteristics

	All (n)	All (%)	Severe and moderate (n)	Severe and moderate (%)
All	10 298		5820	
Birth cohort				
Born between 1987/1988 and 1993/1994 (7 years)	3293	32.0	1979	34.0
Born between 1994/1995 and 1999/2000 (6 years)	7005	68.0	3841	66.0
Sex				
Male	5435	52.8	3389	58.2
Female	4863	47.2	2431	41.8
Ethnicity				
White	8590	83.4	4803	82.5
Non-white	1536	14.9	953	16.4
Black	332	3.2	201	3.5
Asian	897	8.7	561	9.6
Other	307	3.0	191	3.3
Missing	172	1.7	64	1.1
Area of residence deprivation				
Deprived area	4431	43.0	2496	42.9
IMD Q1 (most deprived)	2391	23.2	1310	22.5
IMD Q2	2040	19.8	1186	20.4
Non-deprived area	5867	57.0	3324	57.1
IMD Q3	1954	19.0	1158	19.9
IMD Q4	1931	18.8	1094	18.8
IMD Q5 (least deprived)	1982	19.2	1072	18.4
Model of care				
Vertical model (same site adults and children)	6040	58.7	3368	57.9
Horizontal model (different site adults and children)	4258	41.3	2452	42.1
Complexity score*				
Severe	1454	14.1	1454	25.0
Moderate	4366	42.4	4366	75.0
Mild	4478	43.5		

*Complexity score: severe includes (repaired/unrepaired) double outlet ventricle, functionally univentricular heart (with or without Fontan palliation), interrupted aortic arch, pulmonary atresia (all types), common arterial trunk (truncus arteriosus), heterotaxy syndromes, cyanotic congenital heart disease (unoperated/palliated) and transposition of great arteries (except post arterial switch); moderate includes anomalous pulmonary venous connections, atrioventricular septal defects, coarctation of aorta, repaired tetralogy of Fallot, repaired transposition of great arteries with arterial switch, severe pulmonary valvar disease, aortic subvalvar/supravalvar stenosis and Ebstein anomaly; mild includes isolated unrepaired small septal defects, repaired large septal defects, isolated mild aortic, and pulmonary and mitral valvar disease.
IMD, Index of Multiple Deprivation; Q, quintile.

Patient selection

From the LAUNCHES QI data set, 10 298 patients born between 1 April 1987 and 31 March 2000 aged over 16 years at the time of data collection were studied (figure 1).

Baseline characteristics were determined, including birth cohort (two groups: those born in 1987/1988–1993/1994 and those born in 1995/1996–1999/2000), sex, ethnicity and deprivation quintile. Complexity classification (mild, moderate, severe)

Table 2 Outcomes of 10 298 patients at their 22nd birthday, overall and by complexity group

	n	Transfer to ACHD services n (row %)	Death without transfer n (row %)	Not transferred to ACHD services (alive) n (row %)	Outcome censored before age 22 n (row %)	Estimated probability of transfer at age 22 % (95% CI)
All patients	10 298	6567 (63.8)	42 (0.4)	1402 (13.6)	2287 (22.2)	68.3 (67.3 to 69.3)
Complexity						
Severe	1454	1329 (91.4)	12 (0.8)	19 (1.3)	94 (6.5)	96.5 (95.3 to 97.7)
Moderate	4366	3573 (81.8)	15 (0.3)	264 (6.0)	514 (11.8)	86.7 (85.6 to 87.9)
Mild	4478	1665 (37.2)	15 (0.3)	1119 (25.0)	1679 (37.5)	41.0 (39.4 to 42.6)

The estimated probabilities (conditional probability function) of transfer are conditional on survival of patients and take into account the mortality and censoring of patients.
ACHD, adult congenital heart disease.

in accordance with the current European Society of Cardiology (ESC) guidelines was assigned to each patient using the NCHDA diagnostic and procedural categories and the HES International Classification of Diseases Version 10 (ICD-10) diagnostic codes (see online supplemental material and tables S4-S6).[18] Patients were grouped by whether their paediatric cardiology centre before age 16 employed a horizontal (paediatric services at a separate children's hospital with affiliated ACHD service at a different hospital site) or a vertical (paediatric cardiac services and ACHD services within the same hospital site) model of care. Deprived (Q1, Q2) or non-deprived (Q3, Q4, Q5) status was assigned according to postcode-derived Index of Multiple Deprivation.[19] Further details are given in online supplemental tables S2 and S3.

Main outcome measures

The primary outcome (evidence that transfer from paediatric to ACHD services had occurred) was assigned when the patient was seen in cardiology outpatients or admitted electively as a cardiology inpatient in a recognised UK specialist ACHD centre or a recognised affiliated outreach centre before their 22nd birthday.[11]

Many children with mild lesions are purposefully discharged during childhood as they are not considered to require lifelong ongoing follow-up. Those with mild lesions referred on for adult follow-up may only need to be seen every 4–5 years, so we determined that data collection from ages 16–22 should capture the overwhelming majority of patients. However, all patients with moderate or severely complex conditions would be expected to be seen at least every 2 years with transfer to specialist adult services primarily at ages 16–19 years.[8] We therefore studied a subgroup of patients with moderate or severe disease (n=5824) up to their 20th birthday to minimise the effects of right-censoring of available data and purposeful discharge in the mildly complex group.

Death after age 16 but before transfer was a competing risk to transfer. Life status was ascertained using the ONS mortality registry; patients with missing life status (no linkage to ONS) were censored at last known visit.

We explored factors which may affect transfer, including birth cohort, sex, ethnicity, deprivation and paediatric model of care.

Finally, we examined whether failure to transfer was associated with increased mortality or differences in further procedures between ages 20 and 30.

Statistical analyses

Patient characteristics and outcomes are first described using counts and percentages. Conditional probability functions (CPFs) were fitted to estimate probability of transfer subject to being alive.[20] CPF differences between groups were assessed using Pepe-Mori tests for all pairwise comparisons.[21] CPFs are expressed as average (%, 95% CI).

Single variable and multivariable logistic regressions were used to explore factors potentially affecting transfer, including birth cohort, age at transfer, sex, ethnicity, diagnostic complexity, socioeconomic deprivation and service model for severe and moderate complexity patients. Kaplan-Meier and CPFs were used to estimate the probability of death and reintervention, respectively, between ages 20 and 30 by transfer status at age 20.

RESULTS

The characteristics of the patients are shown in table 1.

The outcomes for the whole cohort (N=10 298) are shown in table 2 and figure 2.

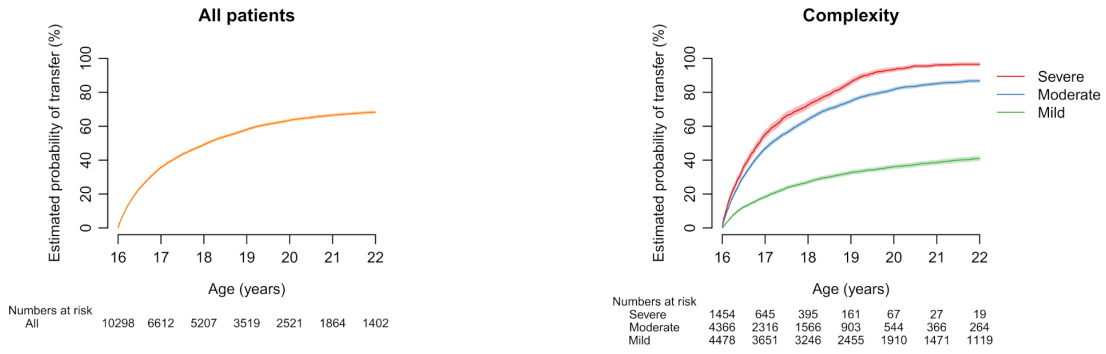

Figure 2 Whole cohort estimated probability of transfer if alive. Overall estimate (left) and by complexity (right) over the follow-up period between the 16th and 22nd birthdays. The estimated probabilities conditional on survival of patients take into account the mortality and right-censoring of patients. Note all complexity conditional probability functions were significantly different pairwise (Pepe-Mori test p<0.001).

Table 3 Outcomes of 5820 severe and moderate patients on their 20th birthday, overall and by group characteristics

	n	Transfer to ACHD services n (row %)	Death without transfer n (row %)	Not transferred to ACHD services (alive) n (row %)	Outcome censored before age 20 n (row %)	Estimated probability of transfer at age 20 % (95% CI)
All severe and moderate complexity	5820	4747 (81.6)	26 (0.4)	611 (10.5)	436 (7.5)	84.7 (83.7 to 85.7)
Complexity						
Severe	1454	1303 (89.6)	12 (0.8)	67 (4.6)	72 (5.0)	93.5 (92.1 to 94.9)
Moderate	4366	3444 (78.9)	14 (0.3)	545 (12.5)	364 (8.3)	81.7 (80.5 to 83.0)
Birth cohort						
Born between 1987/1988 and 1993/1994	1979	1685 (85.1)	15 (0.8)	279 (14.1)	0 (0)	85.8 (84.3 to 87.3)
Born between 1995/1996 and 1999/2000	3841	3062 (79.7)	11 (0.3)	332 (8.6)	436 (11.4)	83.9 (82.5 to 85.2)
Sex						
Male	3389	2799 (82.6)	19 (0.6)	338 (10.0)	233 (6.9)	85.7 (84.5 to 87.0)
Female	2431	1948 (80.1)	7 (0.3)	273 (11.2)	203 (8.4)	83.1 (81.5 to 84.7)
Ethnicity						
White	4803	3975 (82.8)	20 (0.4)	463 (9.6)	345 (7.2)	85.9 (84.8 to 86.9)
Non-white	953	731 (76.7)	6 (0.6)	130 (13.6)	86 (9.0)	79.9 (77.2 to 82.6)
Missing	64	41 (64.1)	0 (0)	18 (28.1)	5 (7.8)	65.9 (53.8 to 77.9)
Area or residence deprivation						
Deprived area	2496	1977 (79.2)	11 (0.4)	294 (11.8)	214 (8.6)	82.5 (80.9 to 84.1)
Non-deprived area	3324	2770 (83.3)	15 (0.5)	317 (9.5)	222 (6.7)	86.2 (85.0 to 87.5)
Model of care*						
Vertical model	3368	2959 (87.9)	10 (0.3)	249 (7.4)	150 (4.5)	89.3 (88.2 to 90.4)
Horizontal model	2452	1788 (72.9)	16 (0.7)	362 (14.8)	286 (11.7)	78.3 (76.5 to 80.1)

The estimated probabilities (conditional probability function) of transfer are conditional on survival of patients and take into account the mortality and censoring of patients.
*Model of care: vertical if paediatric cardiac services and ACHD services are within the same hospital site; horizontal if paediatric services are in a dedicated children's hospital with an affiliated ACHD service at a different hospital site. Details in online supplemental material.
ACHD, adult congenital heart disease.

Of the whole cohort, 63.8% transferred to ACHD services by their 22nd birthday. Of the patients, 166 (1.6%) died between 16 and 22 years; 42 of these (0.4%) died after the age of 16 but prior to transfer. The rates of transfer are determined by complexity. In 22.2% (n=2287) of the whole cohort, there were insufficient years of follow-up in the data set to ascertain their status by their 22nd birthday, but they had not died or had been transferred at the point of censoring.

The estimated probability of transfer by the 22nd birthday (calculated to take account of competing risk of death and right-censoring of data) was 68.3% (95% CI 67.3 to 69.3) for the whole cohort, 96.5% (95% CI 95.3 to 97.7) in the severely complex group, 86.7% (95% CI 85.6 to 87.9) in the moderate group and only 41.0% (95% CI 39.4 to 42.6) in the mild complexity group.

Moderate and severe patients

Transfer and estimated probability (CPF) of transfer by age 20 for the moderate and severe cohort overall and according to our predetermined factors are shown in table 3 and online supplemental figure S2.

Of the moderate and severely complex patients (n=5820), 81.6% (n=4747) were known to have transferred to adult services, 0.4% (n=26) died without transfer occurring, 10.5% (n=611) were known to be alive but had not transferred, and 436 (7.5%) did not have enough years of data to fully assess outcome on their 20th birthday. The estimated probability of transfer in the group as a whole at age 20 was 84.7% (95% CI 83.7 to 85.7).

Single variable and multivariable ORs (95% CI) are shown in table 4. In the multivariable model, moderate complexity (rather than severe) was the factor most likely to determine non-transfer (OR=0.30 (95% CI 0.26 to 0.35), p<0.001), followed by missing ethnicity (OR=0.31 (95% CI 0.18 to 0.52), p<0.001), horizontal model of care (OR=0.44 (95% CI 0.27 to 0.71), p=0.001), deprived area (OR=0.84 (95% CI 0.72 to 0.98), p=0.023) and female sex (OR=0.87 (95% CI 0.78 to 0.98), p=0.014).

Model of care

The multivariable analysis demonstrates that model of care is an important factor in determining transfer of moderate and severe patients. The estimated probability of transfer in the whole cohort at age 22 was 68.8% (95% CI 67.6 to 67.0) in the vertical model and 56.1% (95% CI 54.5 to 57.7) in the horizontal model. In the moderate/severe subgroup, the estimated probability of transfer at age 20 was 89.3% (95% CI 88.2 to 90.4) in the vertical model and 78.3% (95% CI 76.5 to 80.1) in the horizontal model (see table 3). The timing and rate of transfer by model are shown in figure 3.

Transfer occurs significantly earlier in patients in a vertical model than in a horizontal model. Transfer by complexity in each model is shown in figure 3C,D, demonstrating that the timing of transfer is mostly determined by model of care rather than by complexity of the patient.

Patients who have not transferred by age 20

Of the 611 patients in the severe/moderate cohort who had not transferred by age 20 (table 3), 155 (25.4%) subsequently transferred between ages 20 and 22. Of these, 107 (69.0%) were from horizontal centres and 129 (83.2%) were of moderate rather than severe complexity.

Table 4 OR for transfer to ACHD services of severe and moderate patients between age 16 and their 20th birthday, adjusting for covariates one at a time (single variable OR) or together (multivariable OR)

	Single variable OR (95% CI)	Multivariable OR (95% CI)
Birth cohort		
Born between 1987/1988 and 1993/1994	1.11 (0.87 to 1.40)	
Born between 1994/1995 and 1997/1998 (REF)	1.00	
Sex		
Male (REF)	1.00	1.00
Female	0.85** (0.77 to 0.94)	0.87* (0.78 to 0.97)
Ethnicity		
White (REF)	1.00	1.00
Non-white	0.63* (0.40 to 1.00)	0.68 (0.46 to 1.01)
Missing	0.29*** (0.17 to 0.51)	0.31*** (0.18 to 0.52)
Area of residence deprivation		
Non-deprived area (REF)	1.00	1.00
Deprived area	0.75*** (0.65 to 0.85)	0.84* (0.72 to 0.98)
Complexity		
Severe (REF)	1.00	1.00
Moderate	0.33*** (0.28 to 0.38)	0.30*** (0.26 to 0.35)
Model of care		
Vertical (same site) model (REF)	1.00	1.00
Horizontal (not same site) model	0.45** (0.26 to 0.75)	0.44*** (0.27 to 0.71)

The sample consists of 4036 moderate and severe complexity patients born before 1998/1999 (data covering all of their ages between 16 and 20) and alive at age 20 (2 patients were excluded to allow clustering SEs by last centre as child; see online supplemental material): 3425 were transferred to adult services and 611 were not. The multivariable model includes only factors that were significant in the single variable analysis.
***P≤0.001, **P<0.01, *P<0.05.
ACHD, adult congenital heart disease; REF, reference.

Of the 283 patients in the severe/moderate cohort who were known to have not transferred by age 22 (table 2), 57.6% were from horizontal centres despite these patients only making up 42.1% of the overall severe/moderate cohort, demonstrating a shortfall in transfer for patients from horizontal centres even up to age 22. For patients between ages 16 and 22, 26 of 283 were only seen in cardiology at paediatric centres, and a further 89 patients had either an inpatient or outpatient episode in general adult cardiology. Of the remaining 168 patients, it was not possible to identify whether they were sent any cardiac appointments (and failed to attend) or were never sent appointments.

Outcomes in relation to transfer status

Despite complex CHD, the probability of death in both groups remained very low and was not impacted by transfer status: 2.4% (95% CI 0.8 to 4.0) vs 3.9% (95% CI 3.1 to 4.8) (figure 4A). Patients transferred by age 20 had significantly higher probability of undergoing a further NCHDA procedure between ages 20 and 30: 12.3% (95% CI 5.1 to 19.6) vs 32.5% (95% CI 28.7 to 36.3) (figure 4B).

DISCUSSION

Lifelong specialist ACHD follow-up is appropriate for all but the least complex of congenital heart lesions detected in childhood, so as patients enter their teens the process of transition begins. Transition programmes for adolescent patients aim to reiterate the importance of long-term care and to empower patients to take ownership of their own healthcare decisions. Effective transition programmes improve the chance of transfer to adult care,[9] which usually occurs at ages 16–18 depending on the individual needs and comorbidities of the patient. Rate of transfer is only one measurement of effectiveness and does not reflect other aspects of quality of a transition programme, which cannot be captured in routine data collection.

Our data demonstrate a very high rate of transfer to specialist ACHD services in England for patients with severe and moderate lesions, with an estimated probability of transfer of 96.5% for severely complex patients and 86.7% for moderately complex patients by their 22nd birthday. Only 1.3% of severely complex and 6.0% of moderately complex patients are identified as being lost to follow-up at this point, with small numbers of patients with unknown outcomes due to incompleteness of their timelines. Previous studies from Canada and the USA show higher proportions of patients being lost to follow-up.[22 23] Despite these successes, overall, 10.5% of our moderate and complex patient cohort in England did not transfer to specialist adult congenital services by their 20th birthday, with very small numbers of patients continuing to transfer after the age of 20. Gaps in care and lack of regular specialist follow-up are likely to have a detrimental impact on long-term outcomes.[24] It is important that patients in our cohort who do not transfer by age 20 undergo significantly fewer NCHDA procedures in the subsequent decade (figure 4B), suggesting they may be missing out on standard interventions offered relatively routinely to patients under active follow-up.

When we focus on those with moderate and severe complexity, various factors were found to be important for transfer. In our cohort women were slightly less likely to transfer than men and the reasons for this are unclear. Our cohort was unbalanced with regard to gender split at baseline, with more men than women. This gender imbalance in complex CHD is well described and the differences we see may merely reflect subtle differences in patient complexity not captured by our severity groupings.

Transition programmes develop over time, responding to local factors and the changing needs of patients, and as such we may expect to see an increase in effectiveness over time. However, we did not demonstrate any differences in the effectiveness of transfer between our two birth cohorts.

Social deprivation was a significant determinant of failure to transfer care in this study, as has been previously reported.[12 24] While we did not demonstrate a difference between white and non-white groups, patients with 'missing' ethnicity data were less likely to transfer. It is likely that there is overlap and interaction between these two factors, as patients from ethnic minority communities are more likely to reside in areas of higher deprivation.[25]

How we organise care does appear to have a marked impact on both timing and eventual rate of transfer. In England there are two models: vertical model (care from infancy to death at the same institution) and horizontal model (where paediatric care and adult care are in two separate institutions). In our study, patients from a horizontal model were less likely to transfer to adult services by their 22nd birthday, regardless of complexity.

The optimal age for transfer to adult services for individual patients varies depending on their maturity, other health needs and patient preference, but most authors recommend transfer between 16 and 18 years.[26 27] Later transfer may be appropriate in patients with complex needs remaining under the care of multiple paediatric specialties, but this may restrict autonomy of the young adult in relationships with both medical caregivers and parents and limit access to expert advice regarding sexual and reproductive health, more commonly the domain of adult

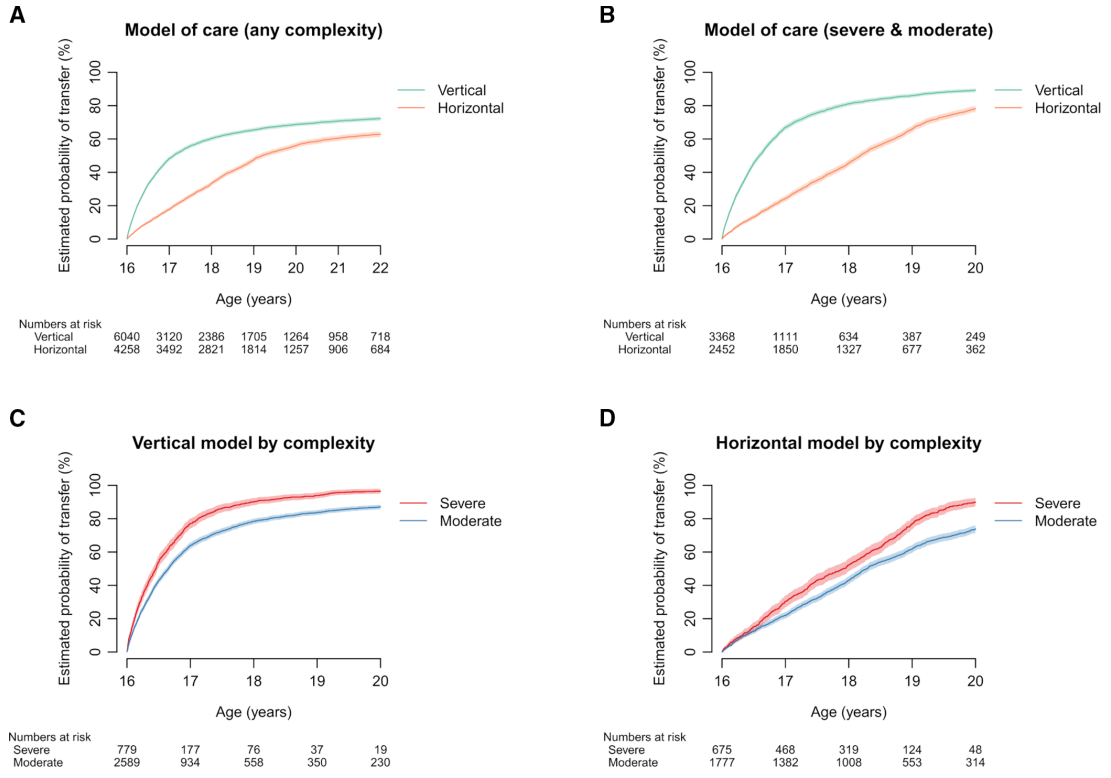

Figure 3 Outcomes by model of care and complexity. (A) Whole cohort by model of care. (B) Severe and moderate complexity by model of care. (C) Severe and moderate patients in the vertical model of care. (D) Severe and moderate patients in the horizontal model of care. The estimated probabilities conditional on survival of patients take into account the mortality and censoring of patients. For each subfigure, the pairs of conditional probability functions were significantly different (Pepe-Mori test p<0.001).

practitioners. Later transfer may also pose difficulties in the event of acute admissions as access to inpatient facilities tends to be determined by age. Conversely, vertical model units transfer the majority of severe and moderately complex patients by age 17 and almost all by age 18. This approach may not necessarily be in the best interests of patients with complex needs, or low levels of maturity, and may reflect a lack of institutional flexibility in how care is best provided. These discussions aside, it remains more likely that patients from a horizontal model will be lost to follow-up at their 22nd birthday.

In our cohort, only 37% of patients with mild lesions, as defined by the ESC guidelines,[18] were transferred to ACHD services by age 22. From this data set it cannot be determined if this low rate of transfer was due to clinically appropriate planned discharge or not. There is increasing evidence that unrepaired, and even repaired, mild lesions do carry an excess of cardiovascular and respiratory morbidity in later life,[28 29] such that it could be argued all of these patients should stay under lifelong follow-up to facilitate access to specialist care and advice regarding non-cardiac surgery, future pregnancy, contraception, genetic risk and endocarditis. This is balanced against personal and healthcare costs of well patients receiving arguably unnecessary follow-up. Our data suggest that a large proportion of patients with mild lesions are discharged prior to adulthood, or are never transfer, and their needs and ways to meet these needs should be studied in more detail.

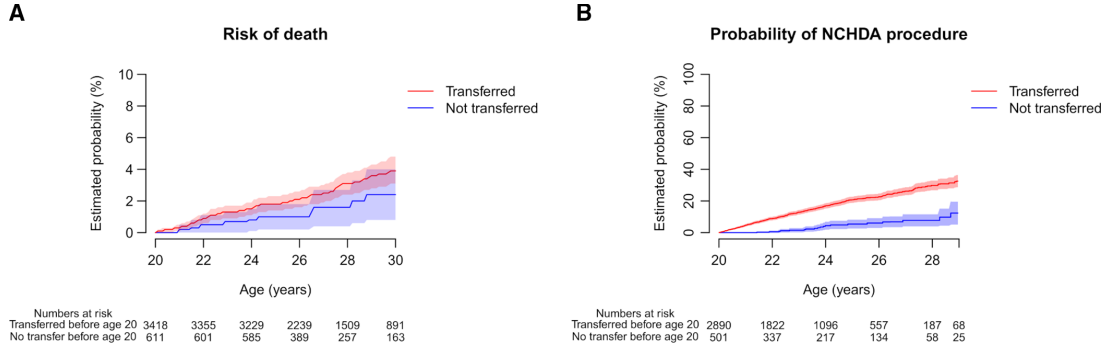

Figure 4 (A) Kaplan-Meier average (%, 95% CI) survival curves by transfer status at age 20. The sample is a subgroup of 4038 severe and moderate patients alive at age 20 and still followed by the data set (born before 1998/1999). (B) Cumulative probability functions of undergoing a further NCHDA procedure between the ages of 20 and 30 by transfer status at age 20. The sample for B is a subgroup of 3391 severe and moderate patients alive at age 20 and still followed by the NCHDA data set (born before 1997/1998). The two conditional probability functions were significantly different (Pepe-Mori test p<0.001). NCHDA, National Congenital Heart Disease Audit.

Only 166 patients (1.6%) died between the ages of 16 and 22 years, with 42 of those dying without transfer to ACHD. In contrast to historical cohorts, the life expectancy curves for patients born with CHD now much more closely mimic those of the general population.[30] The extremely good prognosis for the vast majority of teenagers with CHD is another driver for timely transfer through to adult services in all patients so they can build and develop relationships with their adult team likely to be looking after them for many years to come.

Limitations

Our cohort consisted of patients undergoing a surgical or interventional cardiac procedure as a child. Patients with CHD who did not undergo a procedure were not included. However, the study was likely to capture almost all of those with moderate or severe disease who survived to adulthood.

As in any similar study, the data set had limited granularity and was subject to the limitations of coding and hospital information systems throughout England.

Right-censoring of follow-up data for later births limited some data analyses, with not all patients reaching an event endpoint or age endpoint within the study time. Competing risks analysis (CPF estimation) was performed to minimise this impact.

Recording of ethnicity was incomplete, limiting our analyses into the impact of ethnicity.

There are likely to be other patients born during our study period who had procedures in childhood prior to the NCHDA being set up in the late 1990s, so those born between 1987 and 1997–2000 are likely to be under-represented.

CONCLUSION

Overall, transfer of severe and moderately complex congenital heart patients to specialist adult services in England is extremely effective. Future initiatives should focus on effective care planning for those at increased risk of loss to follow-up. These include transition programmes codesigned with partners from non-white groups and deprived areas to address barriers to transfer. Caregivers in both horizontal and vertical models should consider the demonstrated differences between models of care and whether changes should be made to their current programmes. Those in horizontal models should note evidence of lower numbers successfully transferring overall and further invest in robust links with their ACHD partners. Finally, careful thought should be given to the needs of those with minor lesions in whom there may be increased late morbidity.

Contributors All authors planned the overall study design and analysis. FEP undertook the statistical analysis. RF used his coding expertise to allocate patients to complexity groupings, with clinical assistance from LS and KE. All authors were involved in the writing and approval of the final manuscript. KE is acting as guarantor.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research as part of the LAUNCHES QI project.

Patient consent for publication Not required.

Ethics approval This study was approved by the North of Scotland Research Ethics Committee (trial #18/NS/0106).

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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

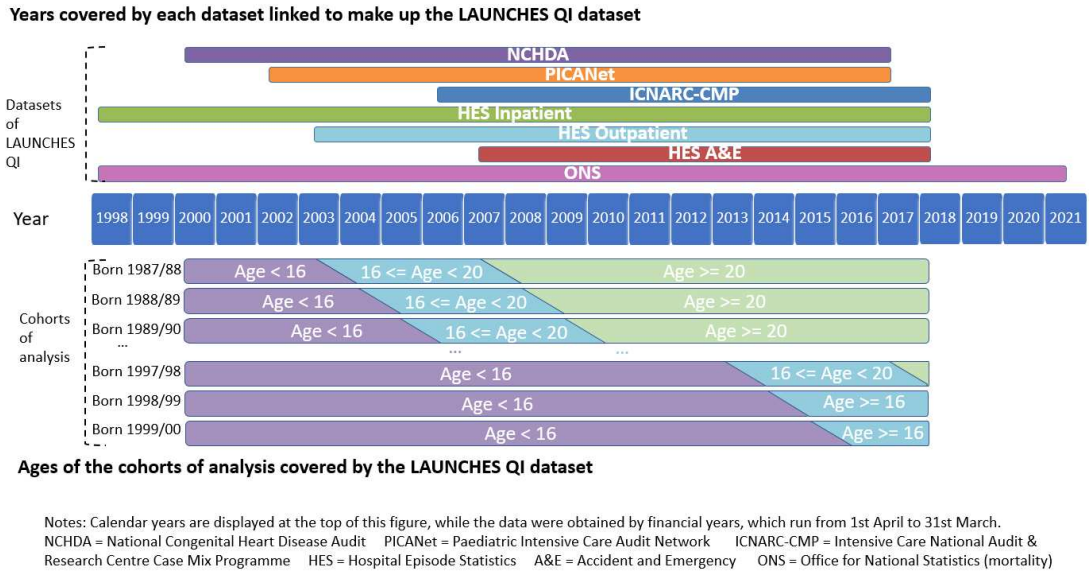
For some patients (depending on their birth cohort as per Figure S1) the data did not cover the whole period of follow-up ages, 16 to end of 19th year or end of 21st year, and right-censored outcomes and time-to-event ages were used (rather than deleting the censored cohorts). Patients' death without 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

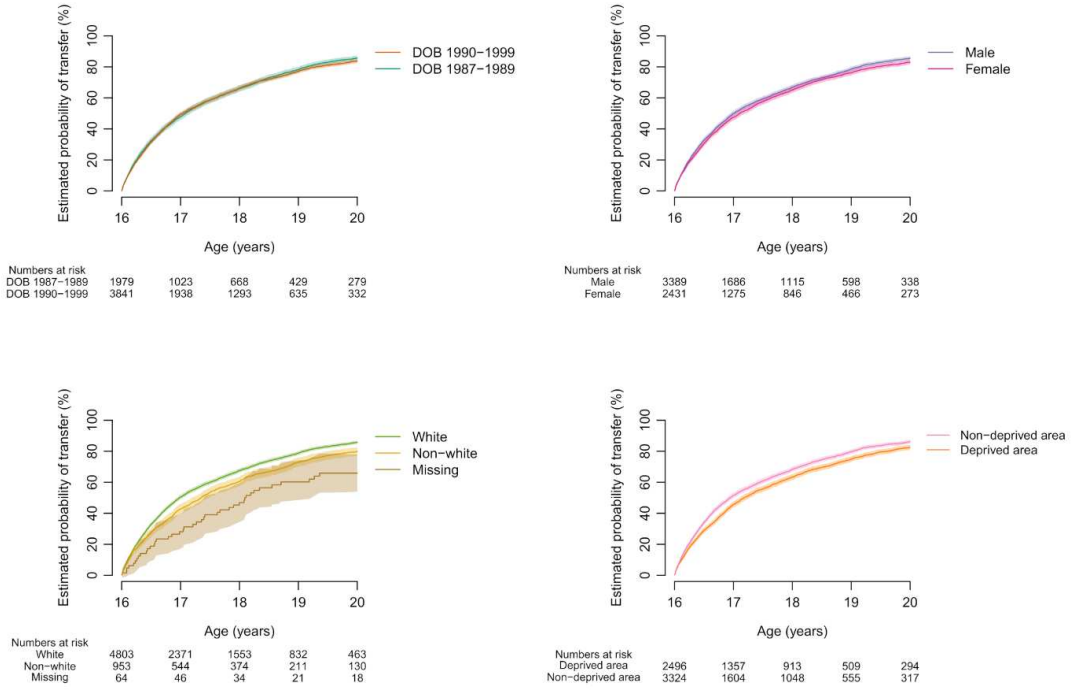
Table S6. Complexity classification assigned to each Specific Procedure category from the NCHDA records in the LAUNCHES dataset.

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).

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

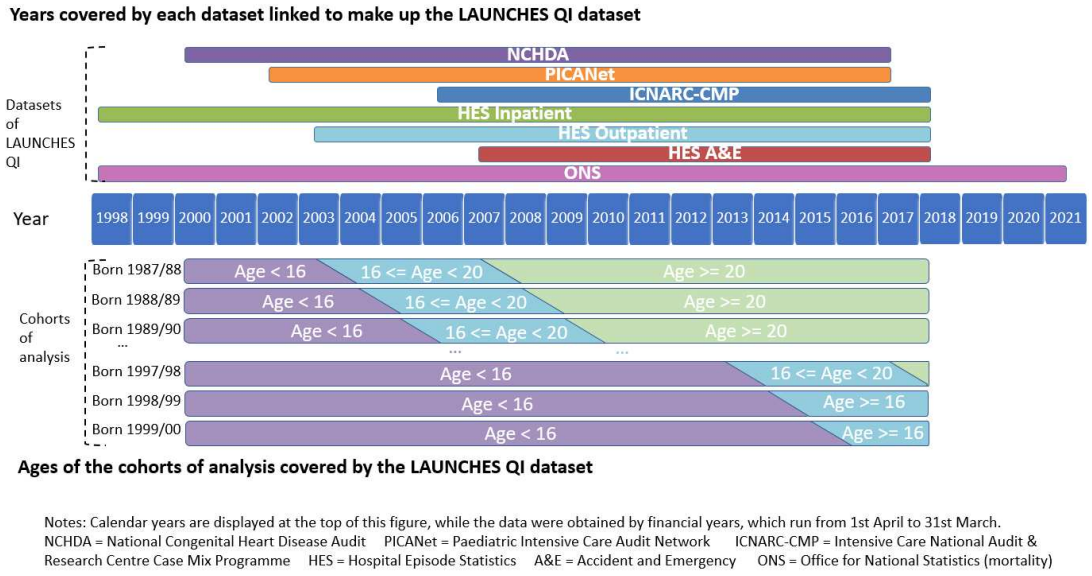
For some patients (depending on their birth cohort as per Figure S1) the data did not cover the whole period of follow-up ages, 16 to end of 19th year or end of 21st year, and right-censored outcomes and time-to-event ages were used (rather than deleting the censored cohorts). Patients' death without 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

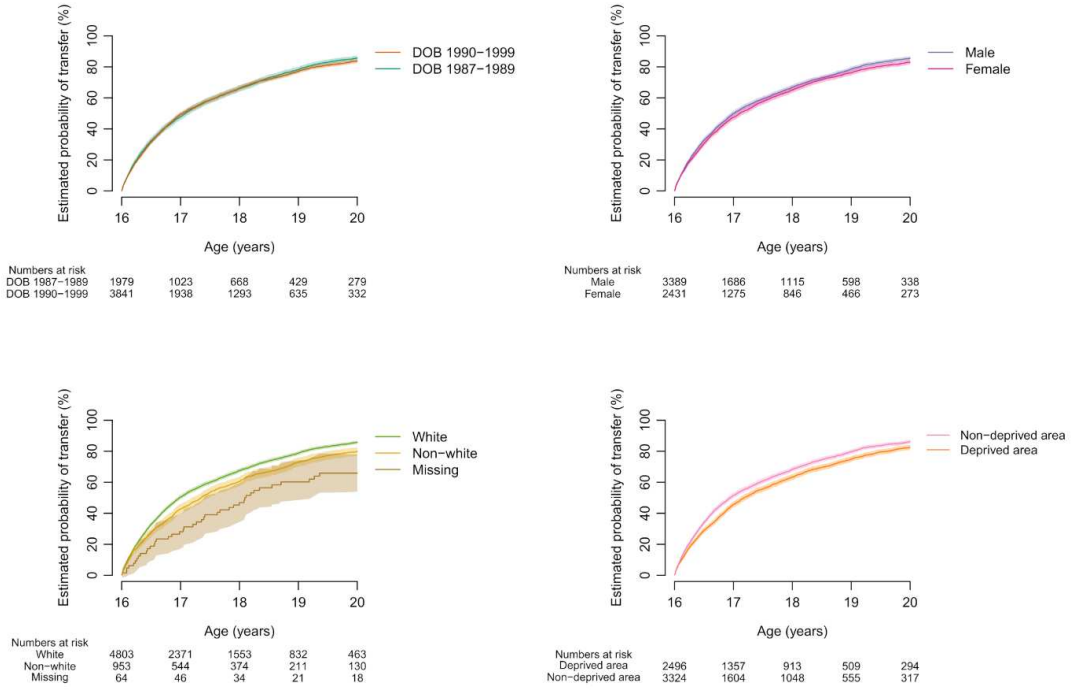
Table S6. Complexity classification assigned to each Specific Procedure category from the NCHDA records in the LAUNCHES dataset.

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).