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Hospital resource utilization in a national cohort of functionally single ventricle patients undergoing surgical treatment

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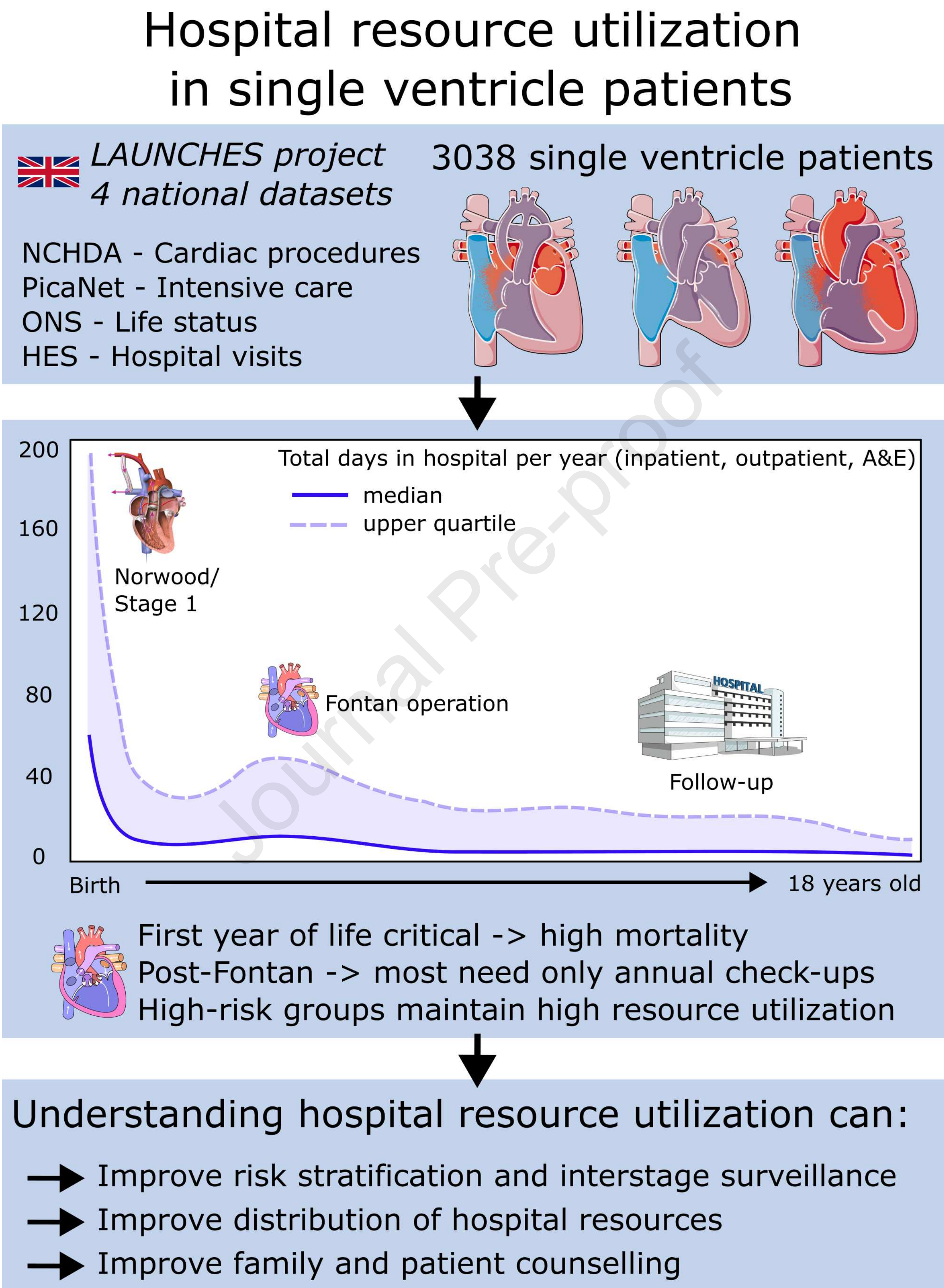
Hospital resource utilization
in single ventricle patients
LAUNCHES project
4 national datasets
3038 single ventricle patients
NCHDA - Cardiac procedures
PicaNet - Intensive care
ONS - Life status
HES - Hospital visits
Total days in hospital per year (inpatient, outpatient, A&E)
median
upper quartile
200
160
120
80
40
0
Norwood/
Stage 1
Fontan operation
HOSPITAL
Follow-up
Birth
18 years old
First year of life critical -> high mortality
Post-Fontan -> most need only annual check-ups
High-risk groups maintain high resource utilization
Understanding hospital resource utilization can:
Improve risk stratification and interstage surveillance
Improve distribution of hospital resources
Improve family and patient counselling

Hospital resource utilization in a national cohort of functionally single ventricle patients undergoing surgical treatment

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Abstract and key words

Objective: To provide a detailed overview of health resource utilization from birth to 18 years old for functionally single ventricle (f-SV) patients and identify associated risk factors.

Methods: All f-SV patients treated between 2000-2017 in England and Wales were linked to hospital and outpatient records using data from the Linking AUdit and National datasets in Congenital HEart Services (LAUNCHES) project. Hospital stay was described in yearly age intervals and associated risk factors were explored using quantile regression.

Results: A total of 3,037 f-SV patients were included, 1409 (46.3%) undergoing a Fontan procedure. During the first year of life the median days spent in-hospital was 60 (IQR 37-102), mostly inpatient days, mirroring a mortality of 22.8%. This decreases to between 2-9 in-hospital days/year afterwards. Between 2-18 years most hospital days were outpatient, with a median of 1-5 days/year.

Lower age at the first procedure, hypoplastic left heart syndrome/mitral atresia, unbalanced atrioventricular septal defect, preterm birth, congenital/acquired comorbidities, additional cardiac risk factors and severity of illness markers were associated with fewer days-at-home and more ICU days in the first year of life. Only markers of early severe illness were associated with fewer days-at-home in the first 6 months post Fontan procedure.

Conclusions: Hospital resource utilization in f-SV is not uniform, decreasing tenfold during adolescence compared to the first year of life. There are subsets of patients with worse outcomes during their first year of life, or with persistently high hospital usage throughout their childhood, which could be the target of future research.

Key words: single ventricle, Norwood, Fontan, hospital length of stay, registry, hospital resources, hypoplastic left heart syndrome

GLOSSARY

A&E – accidents and emergencies (emergency room)

CHD – congenital heart disease

CI – confidence interval

CPB – cardiopulmonary bypass

ECMO - extracorporeal membrane oxygenation

f-SV – functionally single ventricle

HES – hospital episode statistics

HLHS – hypoplastic left heart syndrome

ICU – intensive care unit

IQR – interquartile range

LAUCHES QI – The Linking AUdit and National datasets in Congenital HEart Services for Quality Improvement

NCHDA – National Congenital Heart Disease Audit

ONS – Office for National Statistics

PICANet – pediatric intensive care audit network

Central message

After a resource intensive first years of life, most adolescents with Fontan circulation will only need yearly outpatient visits, with a minority maintaining high hospital resource utilization.

Perspective statement

This study describes in new detail the time spent in hospital as well as outpatient episodes, from birth to adult care in all single ventricle patients receiving at least one intervention. These results can improve how single ventricle associated healthcare resources are distributed by policy makers across age groups, counselling of families and patients and identifying high-risk populations.

Central Picture Legend

Total hospital resource utilization in single ventricle (f-SV) from birth to 18 years old

INTRODUCTION

Functionally single ventricle (f-SV) encompasses a wide variety of congenital heart disease (CHD), where a biventricular circulation cannot be established, currently treated with a three staged approach.[1] Advances in surgical techniques, critical care and follow-up improved their outcomes, which still remain less favourable than other complex CHD. [2–6]

Treatment in f-SV is highly resource intensive, through time spent in hospital, financial and logistical costs.[7–11] Current data focuses on each treatment stage,[12–17] on certain aspects of care such as total hospital costs,[10,11,15] non-cardiac hospitalizations,[7,18] or costs associated with poor outcome.[19] Longitudinal studies, such as the Philadelphia foetus-to-Fontan study,[8] the Australia/New Zealand registry,[20] or the Utah state-wide analysis[21] provide insights into resource utilization associated with f-SV care, but limited to recipients of the Fontan operation, or without discriminating between inpatient or outpatient stay. A complete overview of hospital stays in f-SV including cardiac and non-cardiac, inpatient and outpatient, from birth to adult care is not available. This gap in knowledge limits clinicians' ability to evaluate optimal management, policy makers' ability to allocate resources, and families' opportunities to adjust and plan to what their expected real-life challenges would be, despite this latter point being a major source of anxiety for parents.[22]

As part of the The Linking AUdit and National datasets in Congenital HEart Services for Quality Improvement (LAUCHES QI) project,[23] the current study aims to: 1. Evaluate hospital resource utilization in f-SV treatment, from birth to late adolescence; 2. Investigate factors associated with fewer days spent at home and more days spent in the ICU during the first year of life of infants with f-SV; 3. Report hospital resource utilization following the Fontan procedure, and factors associated with postoperative ICU stay, and fewer days at home within 6 months of the Fontan operation.

PATIENTS AND METHODS

LAUNCHES QI - linking UK national datasets on congenital heart disease care

The LAUNCHES QI project links several national datasets from the UK, evaluating outcomes and hospital resource utilization related to CHD care, with full linkage of all datasets covering England and Wales. These include the National Congenital Heart Disease Audit (NCHDA), which collects procedure based information from all congenital heart disease centres (April 2000-March 2017); the paediatric intensive care audit network (PICANet) for admissions to paediatric intensive care units (ICU) (2001-March 2017); death registrations from the Office for National Statistics (ONS) (up to February 2022); and hospital episode statistics (HES), which contains routine administrative data on inpatient, outpatient and emergency care at hospitals in England (inpatient April 2000-March 2017, outpatient April 2003-March 2017, accidents and emergency department (A&E) April 2007- March 2017).[23] The LAUNCHES project received ethical approval from the Health Research Authority (reference: IRAS 246796) and the Confidentiality Advisory Group (reference: 18/CAG/0180) in accordance with the Declaration of Helsinki.

Clinical data collection, classification, and management

The patient inclusion and exclusion steps are summarized in Figure 1. All clinical data were organised into patient care episodes or “spells”, containing patient events separated by no more than 24 hours,[23] classified as cardiac or non-cardiac. Survival data for a cohort encompassing the currently analysed population was previously reported.[6]

Cardiac diagnosis and procedure codes[24] were used to identify patients with f-SV: firstly, those undergoing biventricular repair were excluded;[3] next, a stepwise algorithm was used to identify HLHS[2] and non-HLHS subtypes.[5]

The following patient/procedure data were extracted from the available datasets (detailed in Supplementary Methods): age and weight, gender, anatomical diagnosis within 8 defined subgroups,[2,3] preoperative risk factors,[25] year of procedures, type of stage 1 procedure,[3] stage 2/stage 3 status, number of off-pathway procedures performed that are not part of the Fontan pathway, such as revisions of the arterial shunts, conduit reinterventions or recoarctation treatment,[2,3] total cardiopulmonary bypass (CPB) time in the 1st year of life (as a surrogate for number and complexity of cumulated surgical procedures), Fontan operation cross clamp duration.

Each dataset has a different start date and end date, and data collection rules vary by time, such as preoperative risk factors being collected systematically after 2009. This has led to each analysis being performed for periods when all required datasets overlapped, mentioned at each respective step. For hospital resource utilization left truncation occurs where data were available only from a given age onwards. Patients presenting in the lower age limit of age intervals who die or are censored before the upper age limit are considered to not have complete hospital utilization data for that interval (right censoring).

In addition, PICANet employs an internal censoring mechanism, where entries of patients older than 18 years old can no longer be identified, so those born before 2002 were not linked.

Details on data collection, classification, and management are available in the Supplementary Methods.

Outcomes

Hospital resource utilization outcomes: 1. days in hospital: total (inpatient, outpatient and A&E), inpatient, outpatient, and ICU days during the first year of life (1-month age intervals) 2. days in hospital: total (inpatient, outpatient and A&E), inpatient, outpatient and ICU days from 0-18 years (one year age intervals) 3. days-at-home during the 1st year of life 4. Inpatient care episode (spell) length and ICU days post Fontan procedure 5. Inpatient days and days-at-home in the first 6 months post Fontan procedure. Care episode length and ICU length of less than one day are counted as one day.

Vital status: Patient life status was provided at the point of hospital discharge by NCHDA for each cardiac procedure and at date of extract by the Office of National Statistics (national death registry data). Any patients with missing ONS life status were censored at their last known live discharge age.

Statistical Analyses

Frequencies are reported as numbers and proportions, and continuous variables as median with inter-quartile range (IQR) and minimum-maximum range, as well as means in Supplemental Tables S2-S9. Any missing values affecting the denominator or leading to exclusions from analyses are detailed where relevant and were not imputed due to the high level of data completeness.

Hospital resource utilization (first year of life and 0-18 years)

Median (IQR) days in hospital/ICU were counted within each age interval. Intervals of one month were used for the first year of life and 1-year age intervals were used for 2-18 years. The numbers of patients who died or were right-censored within each interval are reported (Tables S2-S9).

Factors associated with days-at-home and ICU time analysis

To investigate factors associated with hospital resource utilization, four outcomes of interest were used: days-at-home and days in ICU during first year of life, postoperative ICU days during the Fontan episode (spell) of care, and days-at-home within 6-months post-Fontan. Patients who died before year 1/within 6-months of a Fontan procedure were assigned a value of zero days-at-home as the worst outcome.[26,27] Patients censored in HES/PICANet during the first year of life (or within six-months of Fontan procedure) were excluded from the respective days-at-home/days in ICU analyses.

Quantile regression was carried out to explore factors associated with the median of each outcome of interest, as the data are highly skewed.[28] Effects are presented as univariable and adjusted coefficients and 95% confidence intervals (CI). Clustered standard errors were computed for all models to allow for intra-centre correlation.[28,29] Clinically relevant factors were selected as candidate explanatory variables in the models (detailed in Supplementary Methods).

All statistical analyses were performed using STATA/SE 17.0 (StataCorp LLC, College Station, Texas, USA), and figures created using R version 4.1.2 (R Foundation for Statistical Computing, Vienna, Austria).

RESULTS

A total of 3,037 f-SV patients, with hypoplastic left heart syndrome (HLHS) and other non-HLHS subtypes of f-SV, undergoing their 1st cardiac procedure between April 2000-March 2017 were included (Figure 1). Table 1 shows detailed demographic, clinical, and procedural data for the whole cohort (n=3037), and the Fontan procedure subgroup (n=1,409, 46.3%).

Hospital resource utilization by age intervals

There were 176,751 care episodes (spells) analysed, after exclusion of unattended outpatient episodes (n=23,985) and those with age at admission anomalies (admission age later than age at death, n=213). Of these, 45% were cardiac and the remainder were non-cardiac or ambiguous. By admission type, 19.5% were inpatient and 75.5% outpatient, while 5% were A&E attendance without admission. Of the non-cardiac/ambiguous episodes with reported cause, the most common were: anticoagulant service (8.3%), haematology (6.7%), respiratory conditions (5.2%), dietetics (2.7%) and dentistry (2.5%).

During the first year of life

The median number of days in hospital (inpatient, outpatient or A&E without admission) decreases from 25 days [IQR: 14, 30] in the first month, to 8 days [IQR: 2, 14] in the second month, and to 3-4 days between 3-6 months and 1-2 days between 7-12 months of age (Figure 2, Panel A). Similarly, most inpatient and ICU days were during the first two months of life (Figure 2, Panel B and C respectively.) The outpatient visits in the first year had a median of at most one day/month. (Figure 2, Panel D). Median, IQR, range and mean values as well as the number of deaths and censoring in each age intervals for Figure 2 are provided in Supplemental Tables S2-S5. The majority of hospital days were for cardiac causes.

From birth to 18 years old

The overall median number of days spent in hospital (inpatient, outpatient, or A&E without admission) decreased from 60 days [IQR: 37, 102] for first year of life to fewer than 4 days/year for ages 7-18 years, with a small increase around 3-6 years (the Fontan operation age) (Figure 3, Panel A). A similar pattern is seen in inpatient hospital days/year (from 43 to 0 days/year) (Figure 3, Panel B), and days in ICU/year (from 10 to 0 days/year) (Figure 3, Panel C) and to a lesser degree outpatient days/year (from 8 to 1-3 days/year) (Figure 3, Panel D). Median, IQR, range and mean values for Figure 3 are provided in Supplemental Tables S6-9. A&E without admission amount on average to <1 day/year per patient. Supplemental Tables 6-9 also detail deaths within each 1-year follow-up intervals.

Factors associated with hospital resource utilization during the first year of life

There were 693 (n=22.8%) deaths during the first year of life, mostly in-hospital (n=633/693, 91.3%). During the same period, an ICU admission was recorded in 2,589 (95%) and extracorporeal membrane oxygenation (ECMO) in 122 (4.5%) patients. The number of inpatient days, ICU days and ECMO days during the 1st year of life by survivor status and Stage are shown in Table 2. Non-survivors had fewer inpatient days on average (of them only 10% reached stage 2), but with longer ICU stays and more ECMO days. Most of the resource utilization was related to Stage 1, and less so to Stage 2 procedures. For patients undergoing at least one on-pump procedure, the median total CPB time during the first year of life was 2 hours (IQR 1.4-2.6, range 0.1-10.1).

Factors associated with fewer days spent at home and more days spent in the ICU during the first year of life, from the univariable and multivariable analyses are given in Table 3.

Fontan procedure episode: hospital length of stay and factors associated with days in ICU

The median inpatient stay following the Fontan procedure was 13 days (IQR 10-20, range 1-273), and the median ICU stay following the Fontan procedure was 2 days (IQR 1-3, range 1-257). There were 23 (1.6%) in-hospital deaths, with non-survivors having a median spell length post-Fontan of 23 days (IQR 3-57, range 1-273), and median ICU stay of 22 days (IQR 4-54, range 1-257). One single extreme case (ICU stay of 257 days) required a heart transplant during the same protracted hospital stay.

There were 424 patients born after 2009 with PICANet ICU records included in this analysis, of whom five (1.2%) died following the Fontan procedure. None of the evaluated factors showed a significant association with ICU stay, in univariable or multivariable regression.

6-months post-Fontan: inpatient hospital days and factors associated with fewer days-at-home

In the first 6 months following the Fontan procedure, there were no additional inpatient episodes (spells) in 62.9% of patients, one in 22.7%, two in 8.4%, three or more in in 7% of patients. For those with at least one additional inpatient event, the median inpatient stay was two days (IQR 1-6, range 1-114). There were 30 (2.1%) deaths within 6 months of a Fontan procedure, 22 being in-hospital deaths.

In the adjusted model (n=419 patients born after 2009 with complete HES follow-up or death within 6 months of the Fontan procedure), severity of illness marker at any time before the Fontan operation (coefficient -9.1, CI [-13.2; -5.3], p<0.001) and more exposure to CPB during the first year of life (coefficient -1.3, CI [-2.2; -0.5], p=0.002) were associated with fewer days-at-home within 6 months of the Fontan procedure.

DISCUSSION

This analysis of hospital resource utilization and associated factors in patients with functionally single ventricle offers a comprehensive overview of hospital days from birth to 18 years of age (Figure 4), adding to previous work on s-FV survival and associated risk factors.[6] The main finding is that after a critical first month of life when infants spend most of their time as inpatients, time spent in hospital gradually decreases. It is as low as two days/year (median) for an 18-year-old, transitioning to mostly outpatient-based care in adolescence. This shows a very good clinical course for most Fontan procedure survivors, which is important for counselling.

Equally important but less optimistic, there are a group of patients with high first year mortality or requiring continued high levels of hospitalisation and outpatient visits throughout their childhood and adolescence. Several risk factors have been identified and should be the focus of future research in these subgroups at-risk. Given the significant overlap between these factors associated with hospital resource utilization in survivors, and those previously reported to be linked to mortality,[6] identifying measures to reduce their impact, could result in both lower mortality, and lower morbidity and hospital costs.

The hospital journey of f-SV patients from birth to 18 years old

Management of f-SV is resource intensive, both in hospital stay and financial costs,[7–11,15] especially in Norwood non-survivor cases.[19] Previous research has offered useful information on how hospital days are distributed throughout childhood for f-SV patients, but not without limitations. The Philadelphia fetus-to-Fontan study reported a median of 21.5 days spent in hospital from birth to Stage 1, and a median of two days for the interstage period,[8] however it lacks data beyond Fontan and is limited to single center follow-up. The Australia/New Zealand Fontan registry showed on average under 40 in-hospital days spent during the first year of life and under 10 days/year up to 18 years of age, but with limited details on how these means can be interpreted in the presence of right skewed data.[20] Additionally, both studies focus on survivors of the Fontan procedure and do not differentiate well between inpatient and outpatient care.

The current study provides a highly detailed overview of hospital resource utilization in all f-SV patients with at least one cardiac procedure, from a large geographical area, from birth to 18 years of age, regardless of survival status up-to or after the Fontan procedure, and with a differentiation between hospital visit type and cause. We found that time spent in hospital is concentrated during the first two months of life, when the highest mortality also occurs. Recent results have demonstrated improved interstage survival with continuous hospitalization,[30] and it could be argued that a trade-off between fewer deaths and more hospital days could be acceptable.

Data on care needs beyond the first year of life are limited and difficult to generalise, as they either focus on those who required hospitalizations,[10,18,31] on Fontan survivors,[20] or provide an overall inpatient use up to 10 years of life but without other details.[21] We found that after the age of 6, at least half the patients only require annual follow-up outpatient visits, with median inpatient days per year as low as 0, a lower burden than what was previously reported in older adults.[5,31] This is reassuring, since hospitalizations for non-cardiac causes in f-SV come with high mortality and healthcare costs.[9,18]

There remains considerable right skewness in terms of resource utilization needs, pointing to a subset of individuals with worse outcomes, driving the high mean values like those previously reported.[20,21] The current analysis of factors associated with hospital resource utilization during the initial f-SV palliation builds on previous studies which identified right ventricle anatomy, low weight or critical preoperative status as predictors of various measures of hospital resource utilization, though with smaller sample sizes of 202 to 409 patients,[8,16] as well as a comprehensive analysis of mortality-associated risk factors using the LAUNCHES dataset.[6] The analysis of risk factors accounted for possible center variation, but in a centralised system such as that present in the NHS, the impact of individual center practice on outcomes is low, as recently shown in a study by our group.[6] With further independent replication, comparisons to other forms of CHD and measures of discrimination and calibration, these factors could identify subgroups with differing requirements for monitoring and follow-up. These in turn could be targets for specific research with the aim of implementing quality improvements to address the difference in outcomes demonstrated here.

Informing patients and families

In the era of antenatal diagnosis of CHD, discussions on expected outcomes are crucial and require detailed information. Parents' concerns go beyond survival into how their daily life and that of their children will be affected, among other things, by time spent in the hospital.[22,27]

A diagnosis of f-SV entails a well described early risk of death but information on other aspects of later care is scarce. The current data aims to provide a tool to inform the parents and later the patients themselves. Expectations can be managed based on hard-evidence resulting from a national registry, with figures by age intervals, taking into consideration factors we identified to be associated with fewer days-at-home.

Limitations

This is an analysis of linked national registries, and thus it is limited by data availability but has the advantage of external validation. Analyses were limited to subsets with complete data, leading to exclusions of some patients from certain analyses, preferred to missing data imputation to avoid misclassification. Patient selection was procedure-based excluding cases of neonatal compassionate care or deaths before any intervention. By allocating 0 days-at-home on deaths in the days-at-home analysis, more weight is given to these cases in the quantile regression, although this is mitigated by the fact that they died predominately in-hospital. When comparing hospital resource utilization at different age intervals, survivor bias is inherent, with earlier deaths reflecting the most severe cases. Patients living in Wales might have underestimation of late hospital resource utilization, as non-cardiac local follow-up might not be accurately captured, although these are a small percentage of the total group. There were some ambiguous care episodes (spells), not classifiable as cardiac or non-cardiac, where diagnoses were not noted, and instead a general term "follow-up" was used, reported separately. The analysis on factors associated with health resource utilization was exploratory, and as such causality should not be inferred from it.

Conclusion

This study offers a detailed description of length and type of hospital stay from birth to 18 years and patient-level factors associated with hospital resource utilization, to aid in clinical decision making and counselling. Most of the hospital stay and resource utilization are concentrated in the first two months of life, and decrease substantially over time, transitioning from a predominately inpatient care to mostly outpatient visits. There are those with poor outcomes, including non-survivors, and those with high resource utilization persisting until the age of 18 years old, where identifying modifiable factors could improve quality of care and help narrow the gap in outcomes.

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456 **TABLES**

Table 1. Demographic, clinical, and procedural data in all functional single ventricle (f-SV) patients (n=3,037) and those undergoing the Fontan operation (n=1,409).

Demographic and anthropometric	All patients	Fontan subgroup
Age at first procedure/Fontan, (median, IQR)	6 (3-28) (days)*	4.5 (3.7-5.7) (years)†
Weight, kg (median, IQR)‡	3.2 (2.9-3.8)*	16 (14.4-18.5)†
Low weight <2.5 kg at first procedure, n (%)‡	293 (9.7)	103 (7.3)
Male, n (%)	1,784 (58.7)	847 (60.1)
Anatomical subtype, n (%)		
Hypoplastic left heart syndrome (HLHS)	1,129 (37.2)	404 (28.7)
Single ventricle with isomerism	222 (7.3)	90 (6.4)
Double inlet left ventricle	303 (10.0)	189 (13.4)
Tricuspid atresia	390 (12.8)	224 (15.9)
Non-HLHS Mitral atresia	102 (3.4)	52 (3.7)
Unbalanced atrioventricular septal defect	223 (7.3)	79 (5.6)
Pulmonary atresia	168 (5.5)	95 (6.7)
All other single ventricle	500 (16.5)	276 (19.6)
Preoperative clinical risk factors, n (%)§		
Antenatal diagnosis‖	1,270 (85.5)	364 (85.3)

Preterm birth	122 (8.2)	23 (5.4)
Congenital non-cardiac comorbidity	296 (19.9)	65 (15.2)
Additional cardiac risk factors	120 (8.1)#	15 (3.5)†
Acquired comorbidity	115 (7.8)*	52 (12.2)† 48 (11.2)**
Severity of illness marker	302 (20.3)*	6 (1.4)† 84 (19.7)**
Procedure related factors		
Stage 1 performed, n (%)	2,648 (87.2)	1,201 (85.2)
Stage 1 subtype, n (%)		
Only Norwood	1,276 (42.0)	522 (37.1)
Only hybrid HLHS	89 (2.9)	11 (0.8)
Coarctation/interrupted arch repair	147 (4.8)	81 (5.8)
Securing pulmonary blood flow	785 (25.9)	413 (29.3)
Protecting the pulmonary vascular bed	337 (11.1)	173 (12.3)
Hybrid HLHS followed by Norwood	14 (0.5)	1 (0.1)
Stage 2 performed, n (%)	2,184 (71.9)	1,357 (96.3)
Off-pathway procedure, n (%)	1,495 (49.2)	825 (58.6)
Procedure era, n (%)		

2000-2005	867 (28.5)*	98 (7.0)†
2006-2010	1,030 (33.9)*	476 (33.8)†
2011-2016	1,140 (37.5)*	835 (59.2)†

IQR, interquartile range; first procedure is always first cardiac procedure

* at first procedure

† at Fontan procedure

‡ Missing in n=61 overall and n=45 Fontan patients

§ Reported n=1,485 overall and n=427 Fontan patients (birth since 2009 or later)

|| Missing in n=6 overall and n=1 Fontan patients

during 1st year of life

** before Fontan procedure

Table 2. Hospital resource utilization (number of inpatients, ICU and ECMO days) in the first year of life for functionally single ventricle (f-SV) patients, overall, in non-survivors and in relation to Stage 1 and Stage 2 procedure episodes (spells).

Number of inpatient days*				
	Mean	Median (IQR)	Range	Number of patients
Overall	62.6	43 (25-77)	(0-365)	2,819
Non-survivors	55.3	34 (14-74)	(1-321)	576
Stage 1 related	37.2	22 (11-42)	(0-365)	2,819
Stage 2 related	10.2	1 (0-11)	(0-305)	2,819
Number of ICU days†				
Overall	18.2	10 (4-20)	(0-365)	2,726
Non-survivors	23.7	14 (6-30)	(0-226)	611
Stage 1 related	13.6	7 (2-14)	(0-365)	2,726
Stage 2 related	2.7	0 (0-2)	(0-212)	2,726
Number of ECMO days†				
Overall	1.0	0 (0-0)	(0-121)	2,726
Non-survivors	2.3	0 (0-0)	(0-110)	611
Stage 1 related	0.8	0 (0-0)	(0-121)	2,726
Stage 2 related	0.2	0 (0-0)	(0-78)	2,726

* n=190 patients were not linked to HES and n=28 patients have inpatient episodes (spells) in the 1st of their life without a discharge date, excluded.

† only in patients born in April 2002 or later, due to PICANet censoring data of patients once they reach 18 years of age. Also excluded are n=30 patients were not linked to PICANet for other reasons.

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Table 3. Factors associated with days spent at home and in the intensive care unit (ICU) in the first year of life in functionally single ventricle (f-SV) patients

	Days-at-home (1st year of life)		Days in ICU (1st year of life)	
	Univariate coefficient (95% CI)	Adjusted coefficient (95% CI)	Univariate coefficient (95% CI)	Adjusted coefficient (95% CI)
Clinical subgroup				
Hypoplastic left heart syndrome	-80 (-128.4;-31.6)**	-54.7 (-92.7;-16.7)**	9 (5.1;12.9)***	7.8 (3.4;12.2)***
Single ventricle with isomerism	-11 (-26.3;4.3)	-4.1 (-17.7;9.6)	0 (-2.3;2.3)	0.1 (-2.5;2.6)
Double inlet left ventricle	7 (-21.5;35.5)	2.5 (-14.6;19.6)	-1 (-3.4;1.4)	-0.1 (-2.9;2.6)
Tricuspid atresia	Reference	Reference	Reference	Reference
Mitral atresia	-71 (-105.7;-36.3)***	-55.4 (-96.5;-14.3)**	7 (2.0;11.9)**	5.2 (-0.2;10.6)^
Unbalanced atrioventricular septal defect	-81 (-138.4;-23.6)**	-65.1 (-132.2;2.0)^	6.2 (0.4;12.1)*	3.0 (-1.2;7.3)
Pulmonary Atresia	-9 (-33.7;15.7)	-4.9 (-20.5;10.8)	1 (-1.7;3.7)	0.1 (-2.7;2.8)

All other single ventricle	5 (-16.4;26.4)	-2.1 (-16.2;11.9)	-2 (-4.2;0.2)^	-1.2 (-4.2;1.8)
Male gender	4 (-9.4;17.4)	3.4 (-5.0;11.8)	1 (-1.4;3.4)	0.2 (-1.9;2.2)
Congenital comorbidity	-55 (-74.9;-35.1)***	-31.5 (-46.4;-16.7)***	3 (0.7;5.3)*	2.0 (-0.1;4.2)^
Preterm birth	-75 (-95.3;-54.7)***	-52.5 (-82.4;-22.5)**	4 (-2.0;10.0)	1.4 (-1.1,3.9)
Antenatal diagnosis	-13 (-20.8;-5.2)**	-11.7 (-23.0;-0.4)*	-2 (-4.8;0.8)	0.2 (-2.0;2.3)
Additional cardiac risk (1st year of life)	-100 (-134.7;-65.2)***	-52.8 (-97.0;-8.5)*	15 (9.7;20.3)***	9.6 (2.2;16.9)*
Acquired comorbidity (1st procedure)	-112 (-177.0;-47.0)**	-74.0 (-114.4;-33.5)***	10 (0.3;19.7)*	4.0 (-2.9;10.9)
Severity of illness marker (1st procedure)	-56 (-80.2;-31.8)***	-26.4 (-37.1;-15.8)***	11 (6.7;15.3)***	7.0 (2.2;11.7)**
Low weight <2.5 kg (1st procedure)	-140 (-238.7; -41.3)**	-67.4 (-167.8;33.0)	12 (5.2;18.8)***	7.7 (3.4;12.1)**
Age in months (1st procedure)	2.1 (1.7;2.5)***	1.4 (0.8;2.0)***	-0.5 (-0.7;-0.2)***	-0.3 (-0.5;-0.2)***

Quantile (at median) analysis performed for patients born in April 2009 or later (n=1,485, exclusions below).

N=1 (weight missing) and n=6 (antenatal diagnosis missing) excluded from all regression analysis; n=44 excluded from days-at-home analysis (not linked to HES, censored in HES in 1st year of life or have inpatient episodes (spells) without discharge age in 1st year of life); n=117 excluded from the days in ICU analysis (not linked to PICANet or censored in PICANet in 1st year of life).

If no cardiac procedure in 1st year, related comorbidities marked as “no”.

Coefficients 95% confidence intervals (CI) are from quantile regression at median.

Significance level (p-value): 0.1^, 0.05*, 0.01**, 0.001***

FIGURES LEGENDS

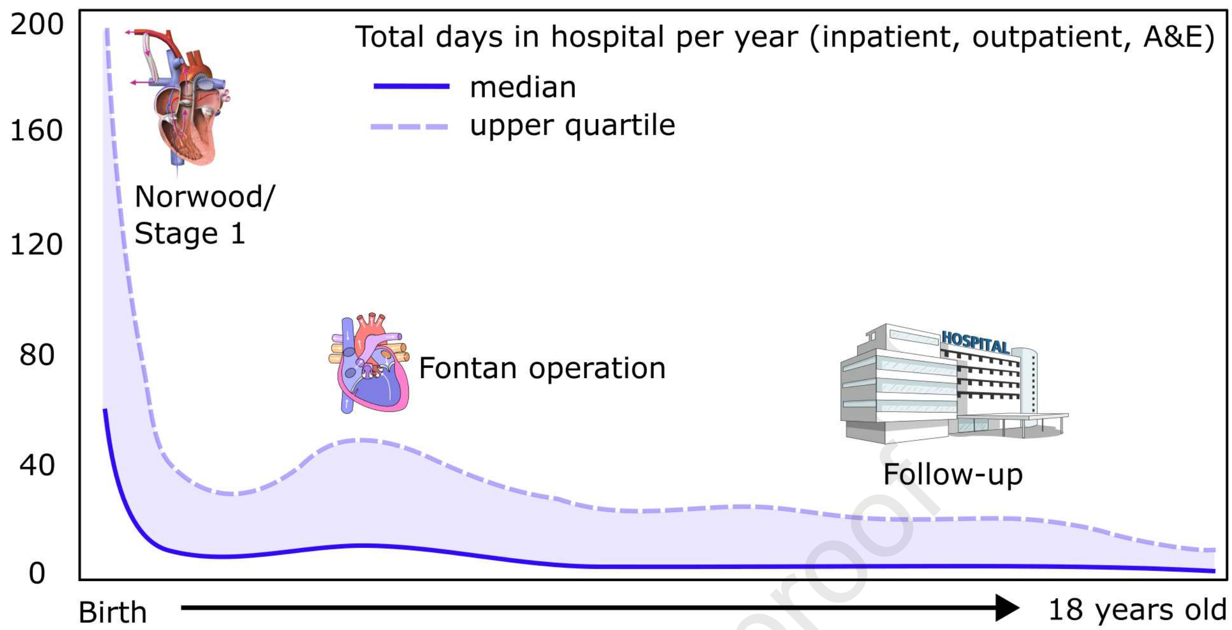
Figure 1. Flowchart of functionally single ventricle (f-SV) study population inclusion and exclusion steps and classifications. Identification of hypoplastic left heart syndrome (HLHS) and non-HLHS patients, and classification into diagnosis types was done using an algorithm described previously[2,3] and further in the Supplemental Materials. NHS, National Health System.

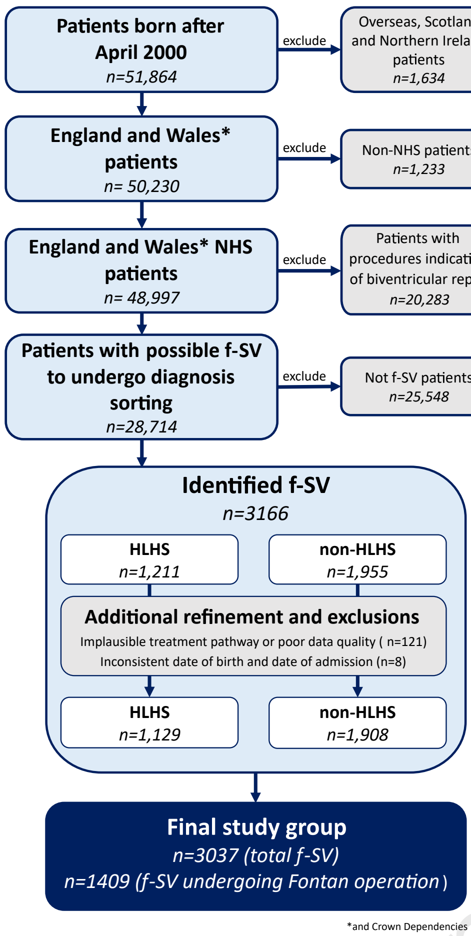
Figure 2. Hospital resource utilization in patients with functionally single ventricle (f-SV) from birth to one year of life. Reported as median number of days/month, within 1-month age intervals. **Panel A**. Total days spent in the hospital (inpatient, outpatient and A&E without admission, cardiac and non-cardiac/ambiguous). **Panel B.** Number of inpatient days (cardiac and non-cardiac/ambiguous). **Panel C.** Days in intensive care unit (ICU). **Panel D.** Number of outpatient days (cardiac and non-cardiac/ambiguous). All panels show the median (horizontal black line line), inter-quartile range (coloured solid bars) and 1.5x inter-quartile range (dotted vertical lines), while outliers outside these limits are not shown. Corresponding numerical values, including means, number of death and censoring in each age intervals are detailed in Supplemental Tables 2-5. ICU data is available for patients who born from 2002 onwards. Patients were included in each consecutive age interval if they had data (linked and available) and were alive or not censored in the lower age limit.

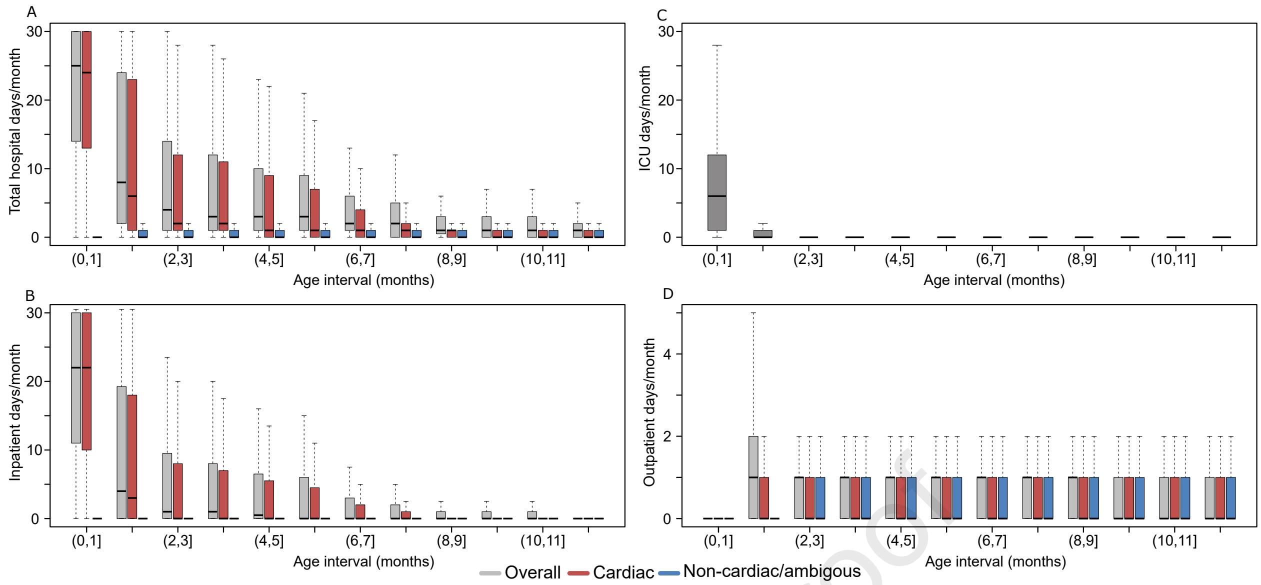
Figure 3. Hospital resource utilization in patients with single ventricle from birth to 18 years of life. Reported as median number of days/year, within 1- year age intervals. **Panel A**. Total days spent in the hospital (inpatient, outpatient and A&E without admission,

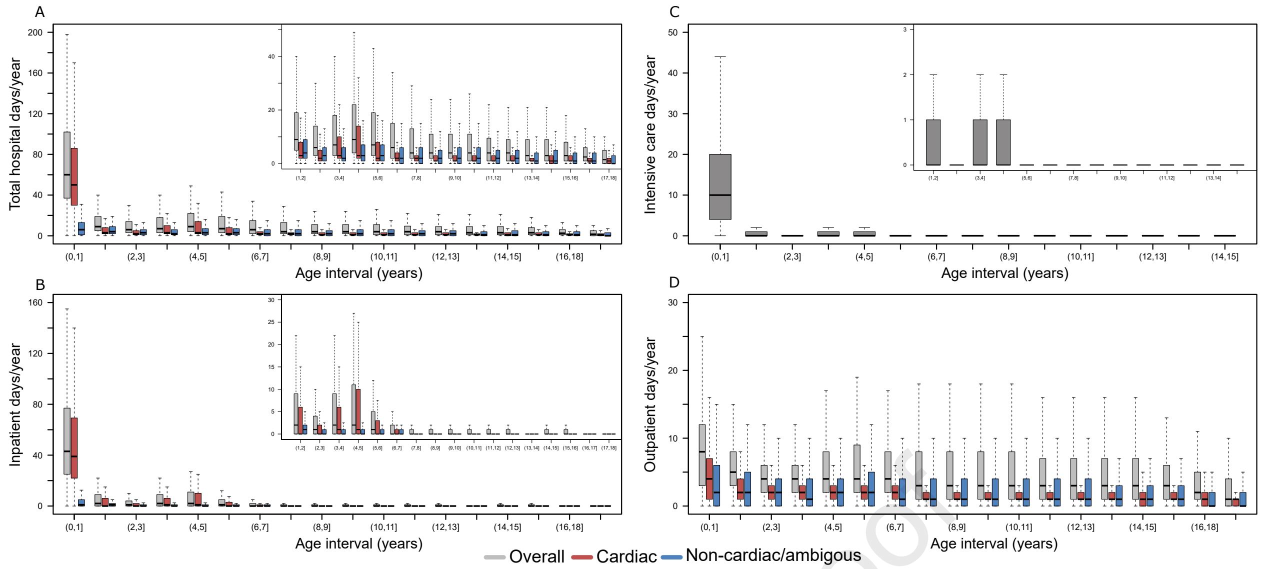
cardiac and non-cardiac/ambiguous). **Panel B.** Number of inpatient days (cardiac and non-cardiac/ambiguous). **Panel C.** Days in intensive care unit (ICU). **Panel D.** Number of outpatient days (cardiac and non-cardiac/ambiguous). All panels show the median (horizontal black line line), inter-quartile range (coloured solid bars bars) and 1.5x inter-quartile range (dotted vertical lines). Inset panels show years 1-18 of life, with adjusted scale, after excluding the first year. Outliers outside these limits are not shown. Corresponding numerical values, including means, number of death and censoring in each age intervals are detailed in Supplemental Tables 6-9. ICU data is available for patients who born from 2002 onwards. Patients were included in each consecutive age interval if they had data (linked and available) and were alive or not censored in the lower age limit.

Graphical abstract/Figure 4. Understanding single ventricle resource utilization and at-risk populations can improve decision making, patient care and counselling.


200
160
120
80
40
0
Total days in hospital per year (inpatient, outpatient, A&E)
median
upper quartile
Norwood/
Stage 1
Fontan operation
HOSPITAL
Follow-up
Birth
18 years old


Patients born after April 2000
n=51,864
exclude
Overseas, Scotland and Northern Ireland patients
n=1,634
England and Wales* patients
n= 50,230
exclude
Non-NHS patients
n=1,233
England and Wales* NHS patients
n= 48,997
exclude
Patients with procedures indicative of biventricular repair
n=20,283
Patients with possible f-SV to undergo diagnosis sorting
n=28,714
exclude
Not f-SV patients
n=25,548
Identified f-SV
n=3166
HLHS
n=1,211
non-HLHS
n=1,955
Additional refinement and exclusions
Implausible treatment pathway or poor data quality (n=121)
Inconsistent date of birth and date of admission (n=8)
HLHS
n=1,129
non-HLHS
n=1,908
Final study group
n=3037 (total f-SV)
n=1409 (f-SV undergoing Fontan operation)
*and Crown Dependencies


A
Total hospital days/month
Age interval (months)
B
Inpatient days/month
Age interval (months)
C
ICU days/month
Age interval (months)
D
Outpatient days/month
Age interval (months)
(0,1]
(2,3]
(4,5]
(6,7]
(8,9]
(10,11]
Overall
Cardiac
Non-cardiac/ambigous

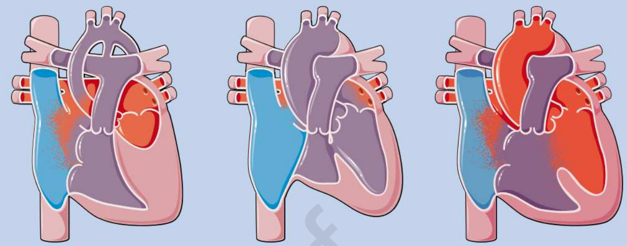

A
Total hospital days/year
Age interval (years)
B
Inpatient days/year
Age interval (years)
C
Intensive care days/year
Age interval (years)
D
Outpatient days/year
Age interval (years)
Overall
Cardiac
Non-cardiac/ambigous

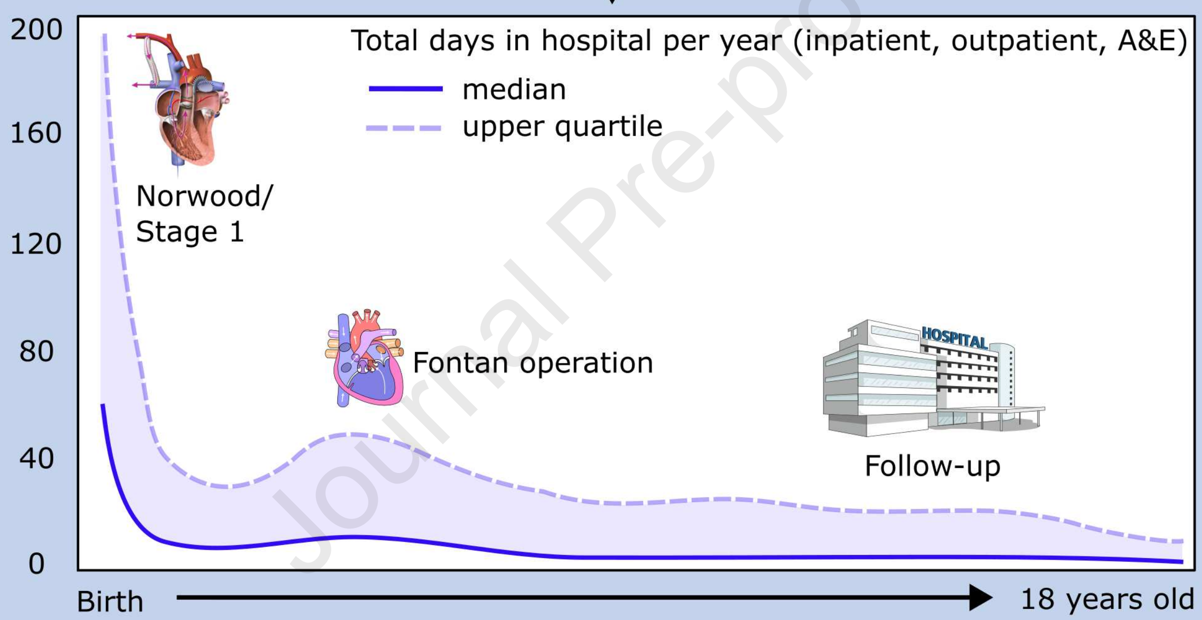
Hospital resource utilization in single ventricle patients

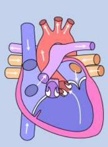
LAUNCHES project
4 national datasets

NCHDA - Cardiac procedures
PicaNet - Intensive care
ONS - Life status
HES - Hospital visits

3038 single ventricle patients







First year of life critical -> high mortality
Post-Fontan -> most need only annual check-ups
High-risk groups maintain high resource utilization

Understanding hospital resource utilization can:

- Improve risk stratification and interstage surveillance
- Improve distribution of hospital resources
- Improve family and patient counselling

SUPPLEMENTAL MATERIALS

Dorobantu et al: Hospital resource utilization in a national cohort of functionally single ventricle patients undergoing surgical treatment

SUPPLEMENTARY METHODS

Data management

Each dataset has a different start date and end date (Supplemental Table S1). This results in each analysis were performed for periods when all required datasets overlapped, which is mentioned at each respective step. In addition, when describing hospital resource utilization, left truncation occurs where data on days spent in hospital/outpatient/A&E were available only from a given age onwards. In the descriptive analysis, patients were included in age intervals where there were data available for the respective interval. Some patients present in the lower age limit of age intervals but die or are censored before the upper age limit and did not have complete hospital data utilization (right censoring). These age intervals were included in the descriptive analysis.

Before 2009, preoperative risk factors were less completely collected in NCHDA dataset. For this reason, the univariable and multivariable analysis of factors associated with hospital resource utilization only included data from 2009 onwards, and their descriptive analysis also reflects this.

In addition, PICANet employs an internal censoring mechanism, where entries of patients older than 18 years old can no longer be identified, so those born before 2002 were not linked.

Patient care spells definition

All clinical data were organised into patient care episodes or “spells”, containing patient events separated by no more than 24 hours.[24] A spell encompasses a single overall health care interaction which can range from a single outpatient appointment or a prolonged inpatient stay. A spell was considered cardiac if it contains an NCHDA procedure or at least one cardiac diagnosis or healthcare resource group code for a HES inpatient stay, outpatient or A&E visit.

Patient selection and classification

The inclusion and exclusion steps are summarized in Figure 1. All patients undergoing a cardiac procedure from the NCHDA audit, born after April 2000 (to ensure procedural history completeness), were considered. To allow for accurate follow-up only those from England and Wales and treated within the National Health Service were included.

Cardiac diagnosis and procedure codes[25] were used to identify patients with f-SV using a hierarchical series of steps: firstly, those undergoing biventricular repair were excluded;[4] next, a stepwise algorithm was used to identify HLHS[3] and non-HLHS subtypes[5] (details in Supplemental Methods). Eight hierarchical diagnosis subgroups were created having at least 100 patients: HLHS, f-SV with any type of atrial isomerism, double inlet left ventricle (DILV), tricuspid atresia, unbalanced common atrioventricular canal defect (uAVSD), mitral atresia without HLHS, pulmonary atresia without other complex features but with a functionally SV circulation and a remaining ‘all other f-SV’.

Data collection and management

The following data were extracted from the available datasets (details by year and data source in Supplemental Table S1): *Data related to patients:* age and weight at first cardiac procedure and at Fontan operation, gender, anatomical diagnosis subtype[3,4] and preoperative risk factors as used by the UK Partial Risk Adjustment in Surgery model for 30-day mortality (2009 and after).[26] Based on weight-for-age Z scores,[27] those records with a Z score > 5 (abnormally high weight) were marked as missing (considered a data entry error), while records with Z score values < -8 (abnormally low weight) were treated as missing only after being reviewed by the study team.

Data related to procedures: year of procedure, type of stage 1 procedure,[4] whether a stage 2 procedure is performed, whether a Fontan procedure is performed, number of off-pathway procedures performed,[3,4] total cardiopulmonary bypass (CPB) time in the 1st year of life (as a surrogate for number and complexity of cumulated surgical procedures), Fontan operation cross clamp duration.

Outcomes

Hospital resource utilization outcomes: 1. days in hospital: total (inpatient, outpatient and A&E), inpatient, outpatient, and ICU days during the first year of life (1-month age intervals) 2. days in hospital: total (inpatient, outpatient and A&E), inpatient, outpatient and ICU days from 0-18 years (one year age intervals) 3. days-at-home during the 1st year of life 4. Inpatient spell length and ICU days post Fontan procedure 5. Inpatient days and days-at-home in the first 6 months post Fontan procedure. Spell length and ICU length of less than one day are counted as one day.

Vital status: Patient life status was provided at the point of hospital discharge by NCHDA for each cardiac procedure and at date of extract by the Office of National Statistics (national death registry data). Death recorded in either NCHDA or ONS was counted as a death, but if death was recorded in both, date of death from NCHDA was used (if there was disagreement). Any patients that were discharged alive in NCHDA and who have missing life status with ONS were deemed lost to follow up and were censored at their last known live discharge age.

Statistical Analyses

Frequencies are reported as numbers and proportions, and continuous variables as median with inter-quartile range (IQR) and minimum-maximum range, as well as means in Supplemental Tables S2-S9. Any missing values affecting the denominator or leading to exclusions from analyses are detailed where relevant and were not imputed due to high level of data completeness.

Hospital resource utilization (first year of life and 0-18 years)

Median (IQR) days in hospital/ICU were counted within each age interval. Intervals of one month were used for the first year of life and 1-year age intervals were used for 2-18 years. The numbers of patients who died or were right-censored within each interval are reported (Tables S2-S9).

Factors associated with days-at-home and ICU time analysis

To investigate factors associated with hospital resource utilization, four outcomes of interest were used: days-at-home and days in ICU during first year of life, postoperative ICU days during the Fontan spell of care, and days-at-home within 6-months post-Fontan. Patients who died before year 1/within 6-months of a Fontan procedure were assigned a value of zero days-at-home as the worst outcome.[27,28] Patients censored in HES/PICANet during the first year of life (or within six-months of Fontan procedure) were excluded from the respective days-at-home/days in ICU analyses.

Quantile regression was carried out to explore factors associated with the median of each outcome of interest, as the data are highly skewed.[29] Effects are presented as univariable and adjusted coefficients and 95% confidence intervals (CI). Clustered standard errors were computed for all models to allow for intra-centre correlation.[30,31]

Clinically relevant factors were selected as candidate explanatory variables in the models. For the models focusing on the first year of life, variables were assigned per patient (clinical diagnosis, gender, preterm birth, congenital non-cardiac comorbidity, documented antenatal diagnosis, additional cardiac risk factor at any time during first year) and for first procedure only (age, low weight<2.5 kg, acquired comorbidity, severity of illness marker). For the models focusing on the post-Fontan period, variables were assigned at patient level (clinical subgroup, subtype of Stage 1, gender, preterm birth, congenital non-cardiac comorbidity, ICU stay during first year of life, days-at-home during first year of life), at the time of the Fontan procedure (age, weight, weight-for-age Z score <-2, acquired comorbidity, cross clamp time) and at any record before the Fontan procedure (acquired comorbidity, severity of illness marker, total CPB in first year of life). The adjusted models include all candidate variables for the models focusing on the first year of life, and those with a univariable $p \leq 0.1$ for the models on post-Fontan procedure period, given that there were few significant variables in the latter.

All statistical analyses were performed using STATA/SE 17.0 (StataCorp LLC, College Station, Texas, USA), and figures created using R version 4.1.2 (R Foundation for Statistical Computing, Vienna, Austria).

Stepwise algorithm to identify hypoplastic left heart syndrome (HLHS) and non-HLHS patients

All diagnosis codes are European Paediatric Cardiac Codes.

HLHS patients[1]

Step 1: Identify HLHS patients

Patients with at least one of the following diagnosis codes:

- 01.01.09: HLHS
- 09.15.03: Aortic atresia
- 06.02.01: Mitral atresia
- 07.08.42: Ventricular imbalance: dominant right ventricle and HLV
- 07.07.00: Left ventricular hypoplasia

OR procedure codes consistent with Stage 1 procedure for HLHS:

- 12.10.00: Norwood type procedure
- 12.09.03: Damus-Kaye-Stansel type procedure: pulmonary trunk to aorta end/side anastomosis **AND** at least one of the following procedure codes indicating Arterial Shunt:
    - 12.31.03: Modified R Blalock shunt
    - 12.31.04: Modified L Blalock shunt
    - 12.31.06: Central systemic-PA interposition shunt
    - 12.31.46: Modified Blalock shunt
    - 12.31.30: Systemic-to-pulmonary arterial shunt procedure

OR procedure codes consistent with stage 1 or stage 2 hybrid for HLHS:

- 12.14.19: Application of right & left pulmonary arterial bands and 12.10.14: stent placement in arterial duct within 4 weeks.
- 12.10.04: Application of bilateral pulmonary arterial bands & transcatheter placement of stent in arterial duct
- 12.20.20: Hypoplastic left heart syndrome hybrid approach (transcatheter & surgery): stage 1
- 12.20.21: Hypoplastic left heart syndrome hybrid strategy (transcatheter & surgery)

- 12.20.22: Hypoplastic left heart syndrome hybrid approach (transcatheter & surgery) 'stage 2': aortopulmonary amalgamation + superior cavopulmonary anastomosis(es) + debanding of pulmonary arteries
- 12.20.23: Hypoplastic left heart syndrome hybrid approach (transcatheter & surgery) 'stage 2': aortopulmonary amalgamation + superior cavopulmonary anastomosis(es) + debanding of pulmonary arteries + arch repair

AND no diagnostic codes indicative of HLHS related malformations from **Methods Appendix 1**

Step 2: Exclusion by treatment pathway not consistent with HLHS

- Removal of patients with only non-contributory or non-cardiac procedures
- Removal of alive patients who had no stage one for HLHS by age three months (allow patients who had pre-pathway then died)
- Removal of BV-like patients who have only pre-pathway with at least one of the codes 123200, 120108, 120103 and 120102. Removal also patients who have pre-pathway with at least one of the codes 120108, 120103 and 120102 and a stage 1/Hybrid (patients who have 123200 pre-pathway and stage1 will NOT be excluded).
- Removal of patients with only pre-pathway and had coarctation procedures (in presence of code 121800, 121801, 121802, 121803, 121810 and 121830).
- Removal of patients who are selected by diagnosis code 070700 only and have no SV procedure and no HLHS procedure.
- Removal of patients who have implausible treatment sequence or too young age at stage 2 (less than 2 months) or stage 3 (less than 6 months).

Non-HLHS patients

These were identified in two stages – Functionally Univentricular Heart (FUH) patients and then other Single Ventricle Patients (other SV)

FUH patients[2]

Step 1: Identify HLHS related malformation patients

Patients with at least one of the following diagnosis codes:

- 01.01.09: HLHS

- 09.15.03: Aortic atresia
- 06.02.01: Mitral atresia
- 07.08.42: Ventricular imbalance: dominant right ventricle and HLV
- 07.07.00: Left ventricular hypoplasia

AND at least one diagnostic codes indicative of HLHS related malformations from **Methods Appendix 1**

Step 2: Identify FUH patients

Removal of any HLHS patients identified in **Step 1 of HLHS**.

Inclusion of HLHS related malformation patients identified in **Step 1 of FUH**.

Inclusion of patients with at least one of the diagnosis codes from **Methods Appendix 2**

Include patients with SV procedures AND at least one of the following diagnosis codes:

- Atrial Isomerism (presence of codes 030104, 030105)
- AVSD (presence of codes 060726, 060709, 060609)
- CCTGA (presence of code 010103)

Step 3: Identify and exclude patients misallocated to the FUH group

Exclusion of patients with at least one of the FUH exclusion diagnostic codes from **Methods Appendix 3**.

Step 4: Exclusion by treatment pathway not consistent with FUH

- Removal of patients with only non-contributory or non-cardiac procedures
- Removal of patients who have implausible treatment sequence or too young age at stage 2 (less than 2 months) or stage 3 (less than 6 months).

Other SV patients

Step 1: Identify and include any remaining other SV patients if

- primary diagnosis as FUH/HLHS

OR

- had SV procedure

Step 2: Identify and include any remaining patients who had

- A Glenn operation: 123111, 123115, 123144, 123145 or 123172 **AND** at least one of the following diagnosis code

- Pulmonary Atresia: 010107, 010106, 090512, 090511 or 010125
- Types of TGA: 010118 or 010501
- CCTGA: 010103
- Ebsteins's malformation of tricuspid valve: 060134
- DORV: 010104, 010117, 010119 or 010140

AND do not have the following procedure code

- Ebstein repair: 120209
- Pulmonary valve or RVOTO opening: 120618,120605, 120600
- Atrial septal defect (ASD) secundum closure with transluminal device: 120106
- Right ventricular outflow tract obstruction relief: 120641
- Ventricular septation procedure: 120901
- 1.5 ventricle repair: superior cavopulmonary (Glenn) anastomosis + right ventricular outflow tract reconstruction: 120619

Step 3: Exclusion by treatment pathway not consistent with other SV

- Removal of patients with only non-contributory or non-cardiac procedures
- Removal of patients who have implausible treatment sequence or too young age at stage 2 (less than 2 months) or stage 3 (less than 6 months).

METHODS APPENDIX 1

03.01.05	Left isomerism ('polysplenia')
03.01.04	Right isomerism ('asplenia')
01.03.09	Atrioventricular and-or ventriculo-arterial connections abnormal
01.01.14	Double inlet atrioventricular connection (double inlet ventricle)
01.04.03	Double inlet right ventricle
01.04.04	Double inlet left ventricle
06.01.01	Tricuspid atresia
01.05.01	Discordant ventriculo-arterial connections (TGA)
01.01.02	Transposition of great arteries (TGA) (concordant atrioventricular & discordant ventriculo-arterial connections) & intact ventricular septum
01.01.03	Congenitally corrected transposition of great arteries (discordant atrioventricular & ventriculo-arterial connections)
01.01.04	Double outlet right ventricle
01.01.17	Double outlet right ventricle: Fallot type (subaortic or doubly committed ventricular septal defect & pulmonary stenosis)
01.01.40	Double outlet right ventricle: subaortic or doubly committed ventricular septal defect without pulmonary stenosis ('VSD type')
01.01.18	Double outlet right ventricle: transposition type (subpulmonary ventricular septal defect)
01.01.19	Double outlet right ventricle: with non-committed ventricular septal defect
01.01.24	Double outlet right ventricle: with intact ventricular septum
01.05.03	Double outlet left ventricle
09.01.01	Common arterial trunk (truncus arteriosus)
09.05.11	Pulmonary atresia
09.05.12	Pulmonary atresia: imperforate valve
01.01.07	Pulmonary atresia + intact ventricular septum
01.01.06	Pulmonary atresia + ventricular septal defect (including Fallot type)
01.01.25	Pulmonary atresia + ventricular septal defect + systemic-to-pulmonary collateral artery(ies) (MAPCA(s))
06.02.09	Straddling mitral valve
06.06.00	Atrioventricular septal defect (AVSD)
06.06.01	Atrioventricular septal defect: isolated atrial component (primum ASD) (partial AVSD)
06.06.08	Atrioventricular septal defect: isolated ventricular component
06.06.10	Atrioventricular septal defect: atrial & (restrictive) ventricular components + separate atrioventricular valve orifices ('intermediate')
06.06.09	Atrioventricular septal defect: atrial & ventricular components with common atrioventricular orifice (complete)
01.01.20	Atrioventricular septal defect and tetralogy of Fallot

06.07.26	Atrioventricular septal defect with ventricular imbalance
06.05.01	Atrioventricular septal defect atrioventricular valvar abnormality
06.05.06	Atrioventricular septal defect atrioventricular valvar regurgitation
07.08.41	Ventricular imbalance: dominant left ventricle + hypoplastic right ventricle
07.02.00	Right ventricular hypoplasia

METHODS APPENDIX 2

01.01.14	Double inlet atrioventricular connection (double inlet ventricle)
01.01.22	Functionally univentricular heart
01.01.24	Double outlet right ventricle with intact ventricular septum
01.04.03	Double inlet right ventricle
01.04.04	Double inlet left ventricle
02.03.05	Solitary ventricle of indeterminate morphology
06.01.01	Tricuspid atresia
06.07.26	Atrioventricular septal defect with ventricular imbalance
07.08.41	Ventricular imbalance: dominant left ventricle + hypoplastic right ventricle
07.08.42	Ventricular imbalance: dominant right ventricle and HLV

METHODS APPENDIX 3

01.01.07	Pulmonary atresia + intact ventricular septum
01.01.25	Pulmonary atresia + ventricular septal defect + systemic-to-pulmonary collateral artery(ies) (MAPCA(s))
01.01.20	Atrioventricular septal defect and Tetralogy of Fallot
09.05.25	Absent pulmonary valve syndrome
09.01.01	Common arterial trunk (truncus arteriosus)

SUPPLEMENTAL TABLES

Table S1. Number of linked records in each dataset by financial year

Financial year	NCHDA	PICANet	A&E	APC	Outpatient
2000	200	0	0	555	0
2001	258	2	0	877	0
2002	271	94	0	1,137	0
2003	379	335	0	1,526	2,499
2004	446	422	0	1,838	3,348
2005	478	513	0	2,195	4,243
2006	592	591	0	2,670	5,614
2007	623	629	618	3,185	7,484
2008	657	624	656	2,957	8,838
2009	724	717	943	3,599	10,878
2010	769	738	1,045	3,833	13,361
2011	798	767	1,116	3,974	14,641
2012	774	687	1,233	3,863	17,490
2013	887	812	1,431	4,144	19,391
2014	993	787	1,707	4,488	24,882
2015	1,256	794	1,901	4,465	27,798
2016	1,136	629	1,870	4,188	26,848
2017	0	0	1,768	3,203	24,825
Total	11,241	9,141	14,288	52,697	212,140

Table S2. Number of days/month spent in hospital (inpatient, outpatient and A&E not admitted) by age intervals during the first year of life **(Numerical data for manuscript Figure 2A)**

Age interval (months)	Days/month Mean			Median [interquartile range] (min-max range)			Patient number		
	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Death (%)	Censoring (%)
(0,1]	21.3	20.6	0.7	25 [14, 30] (0-30)	24 [13, 30] (0-30)	0 [0, 0] (0-30)	1828	145 (7.9)	0 (0)
(1,2]	12.2	11.2	1	8 [2, 24] (0-30)	6 [1, 23] (0-30)	0 [0, 1] (0-30)	1705	73 (4.3)	0 (0)
(2,3]	9	7.9	1.1	4 [1, 14] (0-30)	2 [1, 12] (0-30)	0 [0, 1] (0-30)	1647	45 (2.7)	0 (0)
(3,4]	8.5	7.5	1.1	3 [1, 12] (0-30)	2 [1, 11] (0-30)	0 [0, 1] (0-30)	1615	42 (2.6)	0 (0)
(4,5]	7.5	6.5	1	3 [1, 10] (0-30)	1 [0, 9] (0-30)	0 [0, 1] (0-28)	1584	27 (1.7)	0 (0)
(5,6]	6.8	5.8	1	3 [1, 9] (0-30)	1 [0, 7] (0-30)	0 [0, 1] (0-30)	1568	21 (1.3)	0 (0)
(6,7]	5.6	4.7	1	2 [1, 6] (0-30)	1 [0, 4] (0-30)	0 [0, 1] (0-30)	1558	14 (0.9)	0 (0)
(7,8]	4.8	3.8	1	2 [0, 5] (0-30)	1 [0, 2] (0-30)	0 [0, 1] (0-30)	1567	14 (0.9)	0 (0)
(8,9]	4	3.1	1	1 [1, 3] (0-30)	1 [0, 1] (0-30)	0 [0, 1] (0-30)	1568	12 (0.8)	0 (0)
(9,10]	3.4	2.4	0.9	1 [0, 3] (0-30)	0 [0, 1] (0-30)	0 [0, 1] (0-30)	1562	8 (0.5)	0 (0)
(10,11]	3	2.1	0.9	1 [0, 3] (0-30)	0 [0, 1] (0-30)	0 [0, 1] (0-30)	1572	18 (1.1)	0 (0)
(11,12]	2.4	1.6	0.8	1 [0, 2] (0-30)	0 [0, 1] (0-30)	0 [0, 1] (0-24)	1568	4 (0.3)	0 (0)

Patients were included in each age interval if had HES data (inpatient, outpatient and A&E) and were alive or not censored in HES in the lower age limit. Exclude patients on the age intervals if have inpatient spells without a discharge date. Patients not linked to HES were excluded from the analysis.

Table S3. Number of days/month spent in hospital (inpatient) by age intervals during the first year of life
(Numerical data for manuscript Figure 2B)

Age interval (months)	Days/month Mean			Days/month Median [interquartile range] (min-max range)			Patient number		
	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Death (%)	Censoring (%)
(0,1]	19.9	19.2	0.6	22 [11, 30] (0-30)	22 [10, 30] (0-30)	0 [0, 0] (0-30)	2827	202 (7.1)	0 (0)
(1,2]	10.1	9.6	0.5	4 [0, 19] (0-30)	3 [0, 18] (0-30)	0 [0, 0] (0-30)	2639	97 (3.7)	0 (0)
(2,3]	6.8	6.3	0.5	1 [0, 10] (0-30)	0 [0, 8] (0-30)	0 [0, 0] (0-30)	2542	61 (2.4)	0 (0)
(3,4]	6.3	5.7	0.5	1 [0, 8] (0-30)	0 [0, 7] (0-30)	0 [0, 0] (0-30)	2481	53 (2.1)	0 (0)
(4,5]	5.5	5	0.5	0 [0, 6] (0-30)	0 [0, 6] (0-30)	0 [0, 0] (0-27)	2428	36 (1.5)	0 (0)
(5,6]	5	4.5	0.5	0 [0, 6] (0-30)	0 [0, 4] (0-30)	0 [0, 0] (0-30)	2392	32 (1.3)	0 (0)
(6,7]	4.1	3.6	0.5	0 [0, 3] (0-30)	0 [0, 2] (0-30)	0 [0, 0] (0-30)	2360	21 (0.9)	0 (0)
(7,8]	3.4	2.9	0.5	0 [0, 2] (0-30)	0 [0, 1] (0-30)	0 [0, 0] (0-30)	2339	17 (0.7)	0 (0)
(8,9]	2.7	2.3	0.4	0 [0, 1] (0-30)	0 [0, 0] (0-30)	0 [0, 0] (0-30)	2322	16 (0.7)	0 (0)
(9,10]	2.1	1.8	0.4	0 [0, 1] (0-30)	0 [0, 0] (0-30)	0 [0, 0] (0-30)	2306	15 (0.7)	0 (0)
(10,11]	2	1.5	0.4	0 [0, 1] (0-30)	0 [0, 0] (0-30)	0 [0, 0] (0-30)	2291	22 (1)	0 (0)
(11,12]	1.6	1.3	0.3	0 [0, 0] (0-30)	0 [0, 0] (0-30)	0 [0, 0] (0-28)	2269	7 (0.3)	0 (0)

Patients were included in each age interval if alive or not censored in HES in the lower age limit.

Exclude patients on the age intervals if have inpatient spells without a discharge date. Patients not linked to HES were excluded from the analysis.

Table S4. Number of days/month spent in intensive care unit (ICU) by age intervals during the first year of life
(Numerical data for manuscript Figure 2C)

Age interval (months)	Days/month		Patient number		
	Mean	Median [interquartile range] (min-max range)	Overall	Death (%)	Censoring (%)
(0,1]	8.1	6 [1, 12] (0-30)	2726	240 (8.8)	9 (0.3)
(1,2]	2.6	0 [0, 1] (0-30)	2477	99 (4)	4 (0.2)
(2,3]	1.8	0 [0, 0] (0-30)	2374	61 (2.6)	6 (0.3)
(3,4]	1.7	0 [0, 0] (0-30)	2307	53 (2.3)	12 (0.5)
(4,5]	1.4	0 [0, 0] (0-30)	2242	32 (1.4)	4 (0.2)
(5,6]	1.2	0 [0, 0] (0-30)	2206	31 (1.4)	12 (0.5)
(6,7]	0.9	0 [0, 0] (0-30)	2163	22 (1)	17 (0.8)
(7,8]	0.7	0 [0, 0] (0-30)	2124	15 (0.7)	11 (0.5)
(8,9]	0.6	0 [0, 0] (0-30)	2098	16 (0.8)	11 (0.5)
(9,10]	0.4	0 [0, 0] (0-30)	2071	14 (0.7)	15 (0.7)
(10,11]	0.4	0 [0, 0] (0-30)	2042	22 (1.1)	12 (0.6)
(11,12]	0.3	0 [0, 0] (0-30)	2008	6 (0.3)	4 (0.2)

Patients were included in each age interval if had PICANet data (born since 2002) and were alive or not censored in PICANet in the lower age limit.
Patients not linked to PICANet were excluded from the analysis.

Table S5. Number of days/month spent in hospital (outpatient) by age intervals during the first year of life **(Numerical data for manuscript Figure 2B)**

Age interval (months)	Days/month Mean			Median [interquartile range] (min-max range)			Patient number		
	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Death (%)	Censoring (%)
(0,1]	0.3	0.2	0.1	0 [0, 0] (0-10)	0 [0, 0] (0-5)	0 [0, 0] (0-8)	2514	195 (7.8)	0 (0)
(1,2]	1	0.6	0.4	1 [0, 2] (0-10)	0 [0, 1] (0-9)	0 [0, 0] (0-9)	2324	94 (4)	0 (0)
(2,3]	1	0.6	0.5	1 [0, 1] (0-9)	0 [0, 1] (0-7)	0 [0, 1] (0-8)	2242	60 (2.7)	0 (0)
(3,4]	1	0.6	0.5	1 [0, 1] (0-10)	0 [0, 1] (0-8)	0 [0, 1] (0-7)	2191	51 (2.3)	0 (0)
(4,5]	1	0.5	0.4	1 [0, 1] (0-10)	0 [0, 1] (0-7)	0 [0, 1] (0-8)	2148	32 (1.5)	0 (0)
(5,6]	1	0.5	0.5	1 [0, 1] (0-12)	0 [0, 1] (0-9)	0 [0, 1] (0-10)	2124	32 (1.5)	0 (0)
(6,7]	0.9	0.5	0.4	1 [0, 1] (0-9)	0 [0, 1] (0-7)	0 [0, 1] (0-9)	2101	21 (1)	0 (0)
(7,8]	0.9	0.4	0.4	1 [0, 1] (0-10)	0 [0, 1] (0-10)	0 [0, 1] (0-8)	2091	16 (0.8)	0 (0)
(8,9]	0.9	0.4	0.4	1 [0, 1] (0-12)	0 [0, 1] (0-12)	0 [0, 1] (0-11)	2082	16 (0.8)	0 (0)
(9,10]	0.8	0.4	0.4	0 [0, 1] (0-9)	0 [0, 1] (0-8)	0 [0, 1] (0-9)	2072	14 (0.7)	0 (0)
(10,11]	0.8	0.4	0.4	0 [0, 1] (0-9)	0 [0, 1] (0-9)	0 [0, 1] (0-9)	2066	22 (1.1)	0 (0)
(11,12]	0.7	0.3	0.4	0 [0, 1] (0-11)	0 [0, 1] (0-11)	0 [0, 1] (0-9)	2055	6 (0.3)	0 (0)

Patients were included in each age interval if had outpatient data and were alive or not censored in HES in the lower age limit.

Patients not linked to HES were excluded from the analysis.

Table S6. Number of days/year spent in hospital (inpatient, outpatient and A&E not admitted) by age intervals between 0-18 years **(Numerical data for manuscript Figure 4A)**

Age interval (years)	Days/year Mean			Median [interquartile range] (min-max range)			Patient number		
	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Death (%)	Censoring (%)
(0,1]	79.4	69.6	9.8	60 [37, 102] (0-365)	50 [30, 86] (0-365)	6 [1, 13] (0-255)	1826	414 (22.7)	0 (0)
(1,2]	17.5	9.8	7.6	9 [5, 19] (0-365)	3 [2, 8] (0-365)	4 [2, 9] (0-114)	1580	40 (2.5)	100 (6.3)
(2,3]	11.9	6.8	5.2	6 [3, 14] (0-356)	2 [1, 5] (0-356)	3 [1, 6] (0-73)	1570	22 (1.4)	130 (8.3)
(3,4]	14.3	9.2	5.1	7 [3, 18] (0-365)	3 [2, 10] (0-365)	2 [1, 6] (0-67)	1540	15 (1)	131 (8.5)
(4,5]	16	10.4	5.5	9 [4, 22] (0-360)	3 [2, 14] (0-360)	3 [1, 7] (0-79)	1504	12 (0.8)	153 (10.2)
(5,6]	14	8.6	5.5	7 [3, 19] (0-302)	2 [1, 8] (0-302)	3 [1, 7] (0-66)	1432	9 (0.6)	124 (8.7)
(6,7]	11.3	6.4	4.9	6 [2, 15] (0-365)	2 [1, 4] (0-365)	2 [0, 6] (0-94)	1386	6 (0.4)	144 (10.4)
(7,8]	9.3	4.8	4.6	4 [2, 13] (0-115)	2 [1, 3] (0-115)	2 [0, 6] (0-62)	1342	6 (0.4)	139 (10.4)
(8,9]	8.5	4	4.4	4 [2, 11] (0-120)	1 [1, 3] (0-109)	2 [0, 5] (0-76)	1197	4 (0.3)	151 (12.6)
(9,10]	8.5	4.1	4.4	4 [2, 11] (0-131)	1 [1, 3] (0-129)	2 [0, 6] (0-66)	1042	8 (0.8)	121 (11.6)
(10,11]	8.4	3.9	4.5	4 [1, 11] (0-135)	1 [1, 3] (0-70)	2 [0, 6] (0-115)	913	6 (0.7)	144 (15.8)
(11,12]	7.8	3.7	4.1	4 [1, 10] (0-239)	1 [1, 3] (0-239)	2 [0, 5] (0-50)	763	2 (0.3)	141 (18.5)
(12,13]	7.9	3.9	4	4 [1, 9] (0-123)	1 [1, 3] (0-111)	2 [0, 5] (0-62)	620	2 (0.3)	127 (20.5)
(13,14]	7.6	3.8	3.8	3 [1, 9] (0-218)	1 [1, 2] (0-210)	1 [0, 4] (0-54)	491	0 (0)	110 (22.4)
(14,15]	7.4	3.5	3.9	3 [1, 9] (0-83)	1 [0, 3] (0-74)	1 [0, 5] (0-46)	381	0 (0)	100 (26.2)
(15,16]	6.9	3	3.9	3 [1, 8] (0-59)	1 [1, 3] (0-33)	1 [0, 4] (0-54)	281	0 (0)	93 (33.1)
(16,17]	5.2	2.2	3	2 [1, 6] (0-35)	1 [1, 2] (0-24)	1 [0, 4] (0-31)	188	0 (0)	86 (45.7)
(17, 18]	4.1	1.5	2.6	2 [0, 5] (0-44)	1 [0, 2] (0-38)	0 [0, 3] (0-43)	102	0 (0)	102 (100)

Patients were included in each age interval if had HES data (inpatient, outpatient and A&E) and were alive or not censored in HES in the lower age limit. Exclude patients on the age intervals if have inpatient spells without a discharge date. Patients not linked to HES were excluded from the analysis.

Table S7. Number of days/year spent in hospital (inpatient) by age intervals between 0-18 years
(Numerical data for manuscript Figure 4B)

Age interval (years)	Days/year Mean			Days/year Median [interquartile range] (min-max range)			Patient number		
	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Death (%)	Censoring (%)
(0,1]	62.6	57.6	5	43 [25, 77] (0-365)	39 [22, 69] (0-365)	1 [0, 5] (0-254)	2819	576 (20.4)	0 (0)
(1,2]	10	7.3	2.7	2 [0, 9] (0-365)	0 [0, 6] (0-365)	1 [0, 2] (0-102)	2262	57 (2.5)	100 (4.4)
(2,3]	5.8	4.3	1.5	1 [0, 4] (0-365)	0 [0, 2] (0-365)	0 [0, 1] (0-62)	2104	28 (1.3)	130 (6.2)
(3,4]	7.7	6.3	1.3	2 [0, 9] (0-365)	1 [0, 6] (0-365)	0 [0, 1] (0-70)	1946	18 (0.9)	131 (6.7)
(4,5]	8.2	7	1.2	2 [0, 11] (0-360)	1 [0, 10] (0-360)	0 [0, 1] (0-50)	1798	17 (0.9)	153 (8.5)
(5,6]	6.2	5.2	0.9	1 [0, 5] (0-302)	0 [0, 3] (0-302)	0 [0, 1] (0-45)	1628	9 (0.6)	124 (7.6)
(6,7]	4.2	3.3	0.8	0 [0, 2] (0-365)	0 [0, 1] (0-365)	0 [0, 1] (0-75)	1493	7 (0.5)	144 (9.6)
(7,8]	2.7	2.1	0.6	0 [0, 1] (0-115)	0 [0, 0] (0-114)	0 [0, 0] (0-57)	1342	6 (0.4)	139 (10.4)
(8,9]	2.1	1.4	0.6	0 [0, 1] (0-103)	0 [0, 0] (0-100)	0 [0, 0] (0-51)	1197	4 (0.3)	151 (12.6)
(9,10]	2.1	1.5	0.6	0 [0, 1] (0-125)	0 [0, 0] (0-125)	0 [0, 0] (0-52)	1042	8 (0.8)	121 (11.6)
(10,11]	2	1.2	0.7	0 [0, 1] (0-119)	0 [0, 0] (0-63)	0 [0, 0] (0-101)	913	6 (0.7)	144 (15.8)
(11,12]	1.5	0.9	0.6	0 [0, 1] (0-239)	0 [0, 0] (0-238)	0 [0, 0] (0-38)	763	2 (0.3)	141 (18.5)
(12,13]	1.9	1.4	0.5	0 [0, 1] (0-109)	0 [0, 0] (0-107)	0 [0, 0] (0-22)	620	2 (0.3)	127 (20.5)
(13,14]	1.6	1	0.6	0 [0, 0] (0-207)	0 [0, 0] (0-202)	0 [0, 0] (0-47)	491	0 (0)	110 (22.4)
(14,15]	1.3	0.7	0.5	0 [0, 1] (0-67)	0 [0, 0] (0-60)	0 [0, 0] (0-20)	381	0 (0)	100 (26.2)
(15,16]	1.5	0.8	0.7	0 [0, 1] (0-48)	0 [0, 0] (0-27)	0 [0, 0] (0-47)	281	0 (0)	93 (33.1)
(16,17]	0.8	0.3	0.5	0 [0, 0] (0-32)	0 [0, 0] (0-11)	0 [0, 0] (0-28)	188	0 (0)	86 (45.7)
(17, 18]	0.8	0.6	0.2	0 [0, 0] (0-36)	0 [0, 0] (0-35)	0 [0, 0] (0-9)	102	0 (0)	102 (100)

Patients were included in each age interval if alive or not censored in HES in the lower age limit.
Exclude patients on the age intervals if have inpatient spells without a discharge date. Patients not linked to HES were excluded from the analysis.

Table S8. Number of days/year spent in intensive care unit (ICU) by age intervals between 0-15 years*
(Numerical data for manuscript Figure 4C)

Age interval (years)	Days/year		Patient number		
	Mean	Median [interquartile range] (min-max range)	Overall	Death (%)	Censoring (%)
(0,1]	8.1	10 [4, 20] (0-365)	2726	611 (22.4)	117 (4.3)
(1,2]	2.6	0 [0, 1] (0-141)	1998	51 (2.6)	134 (6.7)
(2,3]	1.8	0 [0, 0] (0-89)	1813	18 (1)	146 (8.1)
(3,4]	1.7	0 [0, 1] (0-225)	1649	17 (1)	157 (9.5)
(4,5]	1.4	0 [0, 1] (0-158)	1475	13 (0.9)	137 (9.3)
(5,6]	1.2	0 [0, 0] (0-36)	1325	8 (0.6)	153 (11.5)
(6,7]	0.9	0 [0, 0] (0-39)	1164	6 (0.5)	145 (12.5)
(7,8]	0.7	0 [0, 0] (0-71)	1013	5 (0.5)	152 (15)
(8,9]	0.6	0 [0, 0] (0-52)	856	2 (0.2)	123 (14.4)
(9,10]	0.4	0 [0, 0] (0-90)	731	3 (0.4)	146 (20)
(10,11]	0.4	0 [0, 0] (0-43)	582	5 (0.9)	144 (24.7)
(11,12]	0.3	0 [0, 0] (0-3)	433	2 (0.5)	125 (28.9)
(12,13]	8.1	0 [0, 0] (0-91)	306	1 (0.3)	113 (36.9)
(13,14]	2.6	0 [0, 0] (0-17)	192	0 (0)	100 (52.1)
(14,15]	1.8	0 [0, 0] (0-7)	92	0 (0)	92 (100)

* No PICANet data on age over 15 years old.

Patients were included in each age interval if had PICANet data (born since 2002) and were alive or not censored in PICANet in the lower age limit.

Patients not linked to PICANet were excluded from the analysis.

Table S9. Number of days/year spent in hospital (outpatient) by age intervals between 0-18 years
(Numerical data for manuscript Figure 4D)

Age interval (years)	Days/year Mean			Days/year Median [interquartile range] (min-max range)			Patient number		
	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Cardiac	Non-cardiac/ ambiguous	Overall	Death (%)	Censoring (%)
(0,1]	8.8	4.7	4.1	8 [3, 12] (0-75)	4 [1, 7] (0-55)	2 [0, 6] (0-70)	2514	557 (22.2)	0 (0)
(1,2]	6.6	2.8	3.8	5 [3, 8] (0-86)	2 [1, 4] (0-49)	2 [0, 5] (0-77)	2058	52 (2.5)	100 (4.9)
(2,3]	5.2	2.2	2.9	4 [2, 6] (0-63)	2 [1, 3] (0-38)	2 [0, 4] (0-57)	1999	26 (1.3)	130 (6.5)
(3,4]	5.5	2.5	3	4 [2, 6] (0-67)	2 [1, 3] (0-66)	1 [0, 4] (0-52)	1951	18 (0.9)	132 (6.8)
(4,5]	6.5	2.9	3.6	4 [2, 8] (0-80)	2 [1, 3] (0-80)	2 [0, 4] (0-60)	1801	17 (0.9)	153 (8.5)
(5,6]	7	3	4	4 [2, 9] (0-55)	2 [1, 3] (0-50)	2 [0, 5] (0-51)	1631	9 (0.6)	125 (7.7)
(6,7]	6.4	2.8	3.6	4 [2, 8] (0-56)	2 [1, 3] (0-51)	1 [0, 4] (0-40)	1497	7 (0.5)	147 (9.8)
(7,8]	6.3	2.7	3.6	3 [1, 8] (0-54)	1 [1, 2] (0-41)	1 [0, 4] (0-52)	1343	6 (0.4)	139 (10.3)
(8,9]	6	2.6	3.5	3 [1, 8] (0-66)	1 [1, 2] (0-38)	1 [0, 4] (0-65)	1198	4 (0.3)	151 (12.6)
(9,10]	6.1	2.6	3.5	3 [1, 8] (0-49)	1 [1, 2] (0-44)	1 [0, 4] (0-47)	1043	8 (0.8)	121 (11.6)
(10,11]	6.1	2.7	3.5	3 [1, 8] (0-59)	1 [1, 2] (0-58)	1 [0, 4] (0-46)	914	6 (0.7)	145 (15.9)
(11,12]	6	2.8	3.3	3 [1, 7] (0-67)	1 [1, 2] (0-67)	1 [0, 4] (0-41)	763	2 (0.3)	141 (18.5)
(12,13]	5.7	2.5	3.2	3 [1, 7] (0-70)	1 [1, 2] (0-69)	1 [0, 4] (0-62)	620	2 (0.3)	127 (20.5)
(13,14]	5.7	2.7	3	3 [1, 7] (0-81)	1 [1, 2] (0-76)	1 [0, 3] (0-44)	491	0 (0)	110 (22.4)
(14,15]	5.8	2.7	3	3 [1, 7] (0-52)	1 [0, 2] (0-51)	1 [0, 3] (0-35)	381	0 (0)	100 (26.2)
(15,16]	5.1	2.2	2.9	3 [1, 6] (0-32)	1 [1, 2] (0-25)	1 [0, 3] (0-30)	281	0 (0)	93 (33.1)
(16,17]	4.1	1.8	2.3	2 [1, 5] (0-27)	1 [0, 2] (0-20)	0 [0, 2] (0-25)	188	0 (0)	86 (45.7)
(17, 18]	3.1	0.9	2.3	1 [0, 4] (0-44)	1 [0, 1] (0-5)	0 [0, 2] (0-43)	102	0 (0)	102 (100)

Patients were included in each age interval if had outpatient data and were alive or not censored in HES in the lower age limit.
Patients not linked to HES were excluded from the analysis.

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