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New Models for Risk-Adjusted Monitoring of Postsurgical Complications and Mortality in Adult Congenital Heart Disease in England and Wales

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ABSTRACT

BACKGROUND Routine monitoring of surgical outcomes can improve service quality. Risk-adjusted monitoring tools for adults with congenital heart disease (CHD) in England and Wales are lacking.

METHODS Using national audit data of all adult CHD surgical procedures in public hospitals from 2015 to 2022, we developed logistic regression models for mortality at 30 days and 90 days and a 30-day complications outcome. Risk factors included patient demographics and categorical derived variables for case complexity and procedure risk. Model performance was assessed by area under the receiver operating characteristic curve and calibration errors for in-sample and cross-validation data sets.

RESULTS Average 30-day and 90-day mortality were 1.4% (49/3502) and 1.7% (58/3493). Moderate and severe CHD complexity were strong predictors of 30-day mortality (odds ratio [95% CI], 3.5 [0.8-15.8], 8.6 [2.4-30.9]), as was high-risk procedure (OR, 3.6 [2.1-6.0]). Average 30-day complication rate was 7.5% (242/3223). Procedure risk groups (OR, 2.4 [0.9-6.0] to 12.2 [4.0-36.8]) and procedure complexity (OR, 2.5 [1.5-4.3]) were the strongest predictors. In cross-validation, 30-day and 90-day mortality models had median discrimination (interquartile range in parentheses) of 0.844 (0.84-0.85) and 0.866 (0.86-0.87), calibration slopes of 1.05 (0.60-1.13) and 1.11 (0.61-1.21), and calibration-in-the-large of 0.00 (−0.12 to 0.19) and −0.07 (−0.17 to 0.30). The 30-day complications model had cross-validation discrimination of 0.760 (0.76-0.76), calibration slope of 0.93 (0.74-1.18), and calibration-in-the-large of −0.07 (−0.13 to 0.22).

CONCLUSIONS The adult CHD risk models perform well for short-term mortality despite a low number of events. The risk model for 30-day complications showed reduced performance, suggesting that important risk factors are not captured by routinely collected data.

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Measuring, reporting, and learning from short-term pediatric survival in congenital heart disease (CHD) has driven

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Abbreviations and Acronyms

ACHD = adult congenital heart disease
AUROC = area under the receiver operating characteristic curve
BMI = body mass index
CHD = congenital heart disease
EPCC = European Paediatric Cardiac Code
NCHDA = National Congenital Heart Disease Audit
NYHA = New York Heart Association
ONS = Office for National Statistics
PEACH = PErioperative ACHd
STS = The Society of Thoracic Surgeons

quality improvement in the United Kingdom. With 97% of children with CHD now surviving into adulthood,[1] the number of CHD adults now outnumbers the pediatric population. The lack of routine retrospective monitoring of adult CHD (ACHD) service outcomes taking into account the patient case mix has thus become increasingly problematic.[2]

In the United Kingdom, the percentage of adults surviving certain CHD procedures is publicly reported by the National Institute of Cardiovascular Outcomes Research as part of the National Congenital Heart Disease Audit (NCHDA) summary report.[3] These are reported against an estimated mortality risk based on a mortality score produced by The Society of Thoracic Surgeons (STS) for ACHD surgical procedures.[4] ACAP (AChd Anatomic Physiological) and PEACH (PErioperative ACHd) are other ACHD mortality scores available, the latter being United Kingdom tailored.[5,6] EuroSCORE, a popular mortality score used for adult acquired cardiac surgery, was developed with the exclusion of ACHD patients.[7] The STS produced a risk model for ACHD postsurgical all-cause death occurring before the latest of 30 days or hospital discharge[8] and investigated the role of reoperation in ACHD mortality and complications.[9] However, these studies use North American patients only and country-specific risk factors. A United Kingdom-specific risk model for ACHD postsurgical composite outcome of postoperative intensive care unit stay longer than a week or death within 6 months of the surgery was produced with use of single-center data.[10]

In this paper, we report the development of 3 new surgical risk models for routine monitoring and reporting of ACHD outcomes in England and Wales. These models were commissioned by the National Institute of Health Research Policy Research Programme and are considered an essential tool for service monitoring. Working with clinicians, patients, and the public, we have defined a set of outcomes that are measurable and objective and developed risk models to take into account the complexity of case mix. Our team of clinical experts included surgeons (V.T., S.S., C.vD., A.L.), cardiologists (R.F., L.C., K.vK.), an intensivist (K.B.), and an expert on clinical data management (J.S.). This manuscript follows the 2024 TRIPOD+AI guidelines for transparent reporting of clinical prediction models.[11]

MATERIAL AND METHODS

DATA. Since April 2000, all congenital cardiovascular procedures for CHD patients in the United Kingdom have been recorded within the NCHDA.[3] Submission is mandatory for all public hospitals, and data quality is subject to external validation. The procedures collected by NCHDA are detailed in Supplemental Figure S1. Cardiac-related diagnosis and procedural information are recorded with the European Paediatric Cardiac Code (EPCC) Short List descriptors.[12] The NCHDA also provides demographic and comorbidity information for CHD procedures, in-hospital survival, and, since April 2015, postoperative complications and several adult-related risk factors.[13]

The Office for National Statistics (ONS) mortality data are the most complete source for the assessment of patient survival, recording all deaths registered in England and Wales.[14]

We obtained NCHDA data for all ACHD surgical procedures between April 2015 and March 2022 carried out in public hospitals in England and Wales (22 centers in total, 11 centers performing most of the procedures). We obtained the ONS life status of patients resident in England and Wales, which represented most of the cohort.

OUTCOMES.

Mortality. Mortality could be reported in several places: NCHDA discharge status, NCHDA 30-day status, or ONS life status. When defining mortality outcomes, we gave priority to NCHDA data and then to ONS linked life status. For records in which mortality status remained unknown, we set it to alive. Supplemental Figure S2 provides a flow diagram describing the mortality definition.

Complications. Postprocedural complications have been collected in NCHDA since April 2015, with some quality limitations during early years. We defined a complications outcome associated with adult surgery as a binary outcome of whether any of the following complications were present at 30

days: unplanned need for a pacemaker, need for renal replacement therapy, postprocedural requirement for tracheostomy, prolonged pleural drainage, use of extracorporeal life support, new neurologic impairment (global or focal), or surgical site infection requiring surgical intervention. Deaths without a recorded complication were excluded from this outcome as a competing risk. Supplemental Table S1 provides a list of EPCC codes used to identify complications.

INCLUDED PROCEDURES. ACHD surgery is more difficult to define than paediatric surgery because some adults undergo surgery for acquired non-congenital heart disease and there is significant unit variation in practice as to which surgeons/teams undertake adult procedures. We aimed to provide the first iteration of a risk-adjusted outcome model for monitoring ACHD programs that could be extended and improved in the future. As such, it needed to be kept as simple and robust as possible and to include only those procedures highly likely to be undertaken solely within a congenital heart program and not as part of a general cardiac surgical program. Therefore, we iteratively identified which procedures to include, adopting a compromise between their frequency (prioritizing most common), their mortality risk (prioritizing high risk), and their treatment variation in ACHD practice (prioritizing least variation). For some procedures, specifically mitral valve repair and replacement and aortic valve repair or replacement, we included them only for adults younger than 40 years because there is ambiguity as to whether the procedure was undertaken by a congenital specialist or general cardiac surgeons.

The NCHDA Specific Procedure v8.05 was used to classify surgical procedures into 1 of 87 categories.[15] Records with "no specific procedure" classification (often where 2 procedures were performed during the same intervention) were assigned to a no specific procedure category. We included the NCHDA no specific procedure surgeries that had procedure codes and ages compatible with inclusion. Supplemental Table S2 contains the list of included specific procedures and the EPCC short codes that defined each of those.

RISK FACTORS.

Demographic. Number of years since age 18 was considered both linearly and using its square root to account for any nonlinearity. Sex was categorized as female or male.

Weight. Weight was recorded in kilograms.

Body Mass Index. Body mass index (BMI) was considered linearly and as a categorical variable with 4 categories: underweight (BMI <18.5 kg/m^2), normal weight ($18.5 \leq$ BMI < 25 kg/m^2), overweight ($25 \leq$ BMI < 30 kg/m^2), and obese (BMI ≥ 30 kg/m^2).

Procedure Risk. Because there were a low number of deaths, we grouped procedures into risk categories informed by running LASSO regression[16] and ratified by our clinical experts.

Procedure Complexity. We defined a procedure complexity score as the number of distinct ACHD procedure codes present in a record. We did not count codes excluded by the Specific Procedure v8.05 algorithm or diagnostic catheter codes (Supplemental Table S3). In addition, we used a list of exclusions (Supplemental Table S4) compiled by a clinical expert cardiologist.

Coronary Artery Bypass Graft. A binary variable indicated whether the procedure included a coronary artery bypass graft.

Nonelective Procedure. A binary variable indicated whether the surgery was nonelective, which included emergency, urgent, and salvage procedures.

Diagnosis Risk. We created diagnosis groupings by adapting mappings from a pediatric risk model.[15,17]

Functionally Univentricular Heart. A binary variable was yes if the procedure or diagnosis codes indicated a functionally univentricular heart (EPCC short codes in Espuny Pujol and coworkers[15]).

Patient Complexity (European Society of Cardiology Based). We assigned a complexity classification (mild, moderate, severe) in accordance with current European Society of Cardiology guidelines using the same methodology as Espuny Pujol and coworkers.[18]

Comorbidity/Additional Risk Factors. Using EPCC codes, we defined the following additional risk factors building on previous work[19] (see Supplemental Table S5 for details): congenital comorbidity, acquired comorbidity, severity of illness, additional cardiac risk factors (eg, endocarditis, preprocedural pulmonary hypertension).

Patient History. We considered the following:[13]

- Sternotomy sequence
- History of ischemic heart disease (later excluded because of data quality issues)
- History of pulmonary disease
- Diabetes status
- Smoking status (later excluded because of data quality issues)
- Poor ventricular ejection fraction (whether left ventricle ejection fraction or right ventricle fractional area change), defined as <30%
- New York Heart Association (NYHA) functional classification, which assigns patients to

TABLE 1 Frequency of Each of the Included ACHD Procedures, 30-Day Outcomes, and Procedure Groups[a]

Specific Procedure v8.05	Frequency	30-Day Mortality	Mortality, SP Groups	30-Day Complications	Complication, SP Groups
Tricuspid valve replacement	154 (4.4)	11 (7.1)	M2 (high)	33 (23.4)	C5 (highest)
Conduit replacement	81 (2.3)	5 (6.2)	M2	6 (8.2)	C3
Mitral valve replacement[b]	132 (3.8)	6 (4.5)	M2	35 (28.0)	C5
Coarctation–hypoplasia of aorta repair	23 (0.7)	1 (4.3)	M2	3 (16.7)	C4
No specific procedure	80 (2.3)	2 (2.5)	M2	5 (6.6)	C3
RV–PA conduit	61 (1.7)	1 (1.6)	M1 (low)	5 (8.3)	C3
Aortic valve repair[b]	70 (2.0)	1 (1.4)	M1	0 (0.0)	C1 (lowest)
Aortic root replacement[b]	293 (8.4)	4 (1.4)	M1	29 (10.5)	C4
Tricuspid valve repair	309 (8.8)	4 (1.3)	M1	22 (7.9)	C3
Mitral valve repair[b]	84 (2.4)	1 (1.2)	M1	1 (1.3)	C1
Pulmonary valve replacement	768 (21.9)	7 (0.9)	M1	36 (5.0)	C2
Aortic valve replacement[b]	460 (13.1)	3 (0.7)	M1	36 (8.7)	C3
Ross procedure	159 (4.5)	1 (0.6)	M1	10 (7.1)	C3
Sinus venosus (ASD and PAPVC)	298 (8.5)	1 (0.3)	M1	11 (4.0)	C2
ASD	429 (12.2)	1 (0.2)	M1	7 (1.8)	C1
AVSD partial	101 (2.9)	0 (0.0)	M1	3 (3.3)	C2
All procedures	3502 (100)	49 (1.4)		242 (7.5)	

[a]Procedures were grouped by mortality frequency (groups M1–M2) and by complications frequency (C1–C5); [b]Aortic and mitral valve procedures were included only for patients 40 years of age or younger. National Congenital Heart Disease Audit "no specific procedure" surgeries were included if their procedure codes and ages were compatible with inclusion. The 30-day complications outcome is reported for 3223 episodes because of data quality limitations. Values are presented as number (percentage). ACHD, adult congenital heart disease; ASD, atrial septal defect; AVSD, atrioventricular septal defect; PAPVC, partial anomalous pulmonary venous connection; RV–PA, right ventricle–pulmonary artery; SP, specific procedure.

categories on the basis of limitations of physical activity[20]

MODEL DEVELOPMENT. We created 30-day and 90-day episodes of care using the first sentinel surgery as the index procedure in case of multiple surgeries within a 30- or 90-day period. Potential risk factors were preselected on the basis of univariate logistic regression ($P < .2$), requiring a minimum frequency (2%) for any category for categorical variables.

Following preselection of risk factors, backward stepwise elimination logistic regression with a significance level of .2 was used to fit the risk models. We fitted all models using list-wise deletion and estimated the standard errors clustering by center. In-sample model performance was assessed by the area under the receiver operating characteristic curve (AUROC). We used 25 times 5-fold cross-validation to evaluate the performance of our ACHD models for in-sample validation. We report median and interquartile range values over the 125 cross-validation runs for the following performance metrics: calibration slope (optimal value of 1), calibration-in-the-large and calibration intercept (both with optimal value of 0), AUROC area (Somers D definition, with optimal value of 1), and Brier score (optimal value of 0).[21]

ETHICAL APPROVAL. The study was approved by the North of Scotland National Health Service Research Ethics Committee (20/NS/0022) and the Health Research Authority Confidentiality Advisory Group (20/CAG/0027), which permits the use of registry data for specific research purposes without consent.

PATIENT AND PUBLIC INVOLVEMENT. An ACHD patient was a member of our research team and chaired a patient and public involvement group, which was consulted about which procedures, risk factors, and outcomes to include within the risk model.

RESULTS

INCLUSION AND OUTCOME. We included 3502 and 3493 surgical episodes for mortality risk adjustment at 30 days and 90 days, respectively (Supplemental Figure S3). The most frequent procedures (Table 1) were pulmonary valve replacement (21.9% [n = 768] 30-day episodes), aortic valve replacement before 40 years of age (13.1% [n = 460]), and atrial septal defect closure (12.2% [n = 429]). Average mortality was 1.4% (n = 49) at 30 days and 1.7% (n = 58) at 90 days. A total of 232 episodes at 30 days and 247 episodes at 90 days had imputed life status (detailed mortality definition results in

TABLE 2 Risk Models for ACHD Postsurgical Outcomes and In-Sample and Cross-Validation Results

Risk Factor	30-Day Mortality Odds Ratio (95% CI)	90-Day Mortality Odds Ratio (95% CI)	30-Day Complications Odds Ratio (95% CI)
Age (years since 18)	1.03 (1.01–1.05)	1.02 (1.01–1.04)	1.02 (1.01–1.02)
Procedure risk M2 (reference: M1 low mortality risk)	3.6 (2.1–6.0)	4.7 (2.6–8.3)	
Procedure risk (complications) (reference: C1 lowest risk)			
C2			2.4 (0.9–6.0)
C3			4.2 (1.9–9.2)
C4			6.6 (2.0–21.1)
C5 (highest risk)			12.2 (4.0–36.8)
Complex procedure	3.3 (1.9–5.7)	2.9 (1.7–4.9)	2.5 (1.5–4.3)
Nonelective procedure	2.0 (1.0–3.7)		1.9 (1.3–2.7)
Patient complexity (reference: mild)			
Moderate complexity	3.5 (0.8–15.8)	3.5 (0.8–4.7)	
Severe complexity	8.6 (2.4–30.9)	4.6 (1.3–16.4)	
Congenital comorbidity	2.4 (1.6–3.7)	2.4 (1.5–3.8)	1.5 (1.1–2.0)
Acquired comorbidity		2.1 (1.3–3.5)	1.4 (1.0–2.0)
Additional cardiac risk factors	2.0 (1.0–3.9)	2.6 (1.2–5.6)	
At least third sternotomy		1.8 (0.9–3.6)	1.7 (1.1–2.6)
NYHA physical activity limitations	2.4 (1.1–5.4)	2.6 (1.3–5.3)	1.3 (0.9–1.7)
Poor ventricular ejection fraction	1.6 (0.9–3.1)	1.8 (1.0–3.1)	2.1 (1.1–4.0)
No. of surgeries (events)	3486	3410	3155
In-sample AUROC, average (95% CI)	0.865 (0.82–0.91)	0.882 (0.84–0.92)	0.772 (0.74–0.80)
25 Times 5-Fold Cross-Validation Errors	**30-Day Mortality Median (IQR)**	**90-Day Mortality Median (IQR)**	**30-Day Complications Median (IQR)**
Calibration slope (ideal 1)	1.05 (0.60–1.13)	1.11 (0.61–1.21)	0.93 (0.74–1.18)
Calibration-in-the-large (ideal 0)	0.00 (−0.12 to 0.19)	−0.07 (−0.17 to 0.30)	−0.07 (−0.13 to 0.22)
AUROC area (ideal 1)	0.844 (0.84–0.85)	0.866 (0.86–0.87)	0.760 (0.76–0.76)
Brier score (ideal 0)	0.015 (0.01–0.02)	0.016 (0.01–0.02)	0.061 (0.06–0.08)

ACHD, adult congenital heart disease; AUROC, area under the receiver operating characteristic curve; IQR, interquartile range; NYHA, New York Heart Association.

Supplemental Material). LASSO regression followed by expert review resulted in 2 procedure risk groups for mortality outcomes (eg, at 30 days: high 5.3% mortality [n = 470 episodes] and low 0.8% mortality [n = 3032]), which were consistent between the 30-day and 90-day mortality outcomes.

For 30-day complications, we removed 268 episodes with missing outcome and 11 episodes with death before 30 days without complication (considered a competing event). See Supplemental Table S6 for the frequencies of the included complications. The most frequent complications were complete atrioventricular block requiring permanent pacemaker (3.2% [n = 102]), acute kidney injury requiring dialysis (2.1% [n = 68]), and need for postprocedural mechanical circulatory support (1.3% [n = 43]).

Average 30-day complication rate was 7.5% (242/3223). The procedures with highest complication rates were mitral valve replacement (28.0%) and tricuspid valve replacement (23.4%), with mortality rates of 4.5% and 7.1%, respectively. LASSO followed by expert review resulted in 5 complication risk groups (varying between 266 and 1088 episodes and between 1.5% and 25.6% complications at 30 days). The full procedure results and their groupings for risk adjustment are in Supplemental Table S7 for mortality and Supplemental Table S8 for complications (summary in Table 1).

PRESELECTION OF RISK FACTORS. Univariate logistic regression results are shown for each of the 3 modeled outcomes in Supplemental Tables S9 to S11 for continuous risk factors (eg, weight in kilograms) and in Supplemental Tables S12 to S14 for categorical risk factors (eg, sex). The following risk factors were preselected for consideration in the multivariate models based on univariate analysis and sample size (for both mortality and the complications models unless stated otherwise):

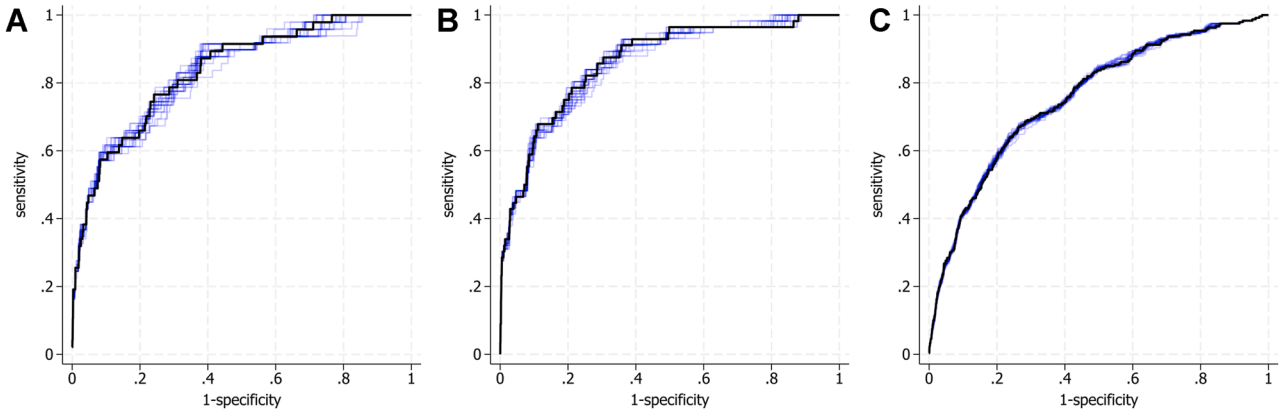

FIGURE Receiver operating characteristic (ROC) curves for (A) 30-day survival, (B) 90-day survival, and (C) 30-day complications. Each of the 25 times 5-fold cross-validation ROC curves is plotted with a light blue thin line (the darker the color, the bigger the overlap between ROC curves). The ROC curve with median Somers area under the ROC value is represented with a black wide line.

- Demographics: age and its square root; sex (only for complications)
- BMI: only for mortality models (either as linear factor or BMI groups)
- Procedure: specific procedure groups M1-M2 for mortality and C1-C5 for complications
- Procedure complexity: whether 4 or more ACHD procedure codes
- Nonelective: whether nonelective surgery
- Patient complexity: the European Society of Cardiology-based patient complexity classification
- Comorbidity: congenital comorbidity; acquired comorbidity; additional cardiac risk factors
- Patient history: sternotomy sequence; history of pulmonary disease (only for 90-day mortality); NYHA status; poor ventricular ejection fraction

RISK MODELS AND VALIDATION. Table 2 shows the final risk models. The most predictive categorical risk factors for adjusted (30-day and 90-day) postsurgical mortality were patient complexity and procedure risk. The most predictive categorical risk factors for 30-day postsurgical complications were procedure risk and procedure complexity (ie, having multiple recorded congenital procedure codes).

Cross-validation results showed a median AUROC (interquartile range in parentheses) of 0.84 (0.84-0.85) for 30-day survival, 0.87 (0.86-0.87) for 90-day survival, and 0.76 (0.76-0.76) for complications; close-to-one calibration slopes; and close-to-zero calibration-in-the-large values (Figure).

COMMENT

PRINCIPAL FINDINGS. We have developed 3 new ACHD risk models predicting postsurgical mortality at 30 days and 90 days and a 30-day composite complications outcome. The risk factors included in our models were age, procedure risk, procedure complexity, nonelective procedure, patient complexity, congenital comorbidity, acquired comorbidity, additional cardiac risk factors, at least third sternotomy, NYHA physical activity limitations, and poor ventricular ejection fraction.

A total of 3502 sentinel 30-day surgical index procedures were included from the UK NCHDA data set from 2015-2016 to 2021-2022. The strongest predictors of 30-day (1.4%) and 90-day (1.7%) mortality in our models (other than age) were non-mild patient complexity, defined by the European Society of Cardiology guidelines[18]; and high-risk procedures, which included tricuspid valve replacement, conduit replacement, mitral valve replacement, coarctation-hypoplasia of the aorta repair, and multiple procedures during the same intervention (which falls into a no specific procedure class). Procedure urgency was relevant for predicting 30-day mortality, whereas at 90 days, other factors like at least third sternotomy and acquired comorbidities were more relevant.

A composite 30-day complication outcome (prevalence 7.5%) was defined, the most frequent complications being complete atrioventricular block requiring a permanent pacemaker (3.2% [n = 102]) and acute kidney injury requiring dialysis (2.1% [n = 68]). High-risk procedures included mitral valve replacement, tricuspid

valve replacement, coarctation-hypoplasia of aorta repair, and aortic root replacement.

The discrimination power of mortality models was good (high AUROC), whereas it was less so for the complications model. All model predictions aligned well with the actual outcomes (good calibration).

COMPARISON WITH OTHER STUDIES. Our models are uniquely representative of a national universal health system and contrast with the STS models, which use North American mixed health care data (private and publicly financed), and the adult congenital PEACH score using a single center in the United Kingdom.[6] They are specific to the ACHD population, unlike the EuroSCORE II.[7] Our models' risk factors were consistent with the STS adult congenital mortality risk model,[8] the EuroSCORE II, and the PEACH score. Details are provided in the Supplemental Material section "Comparison with other studies."

STRENGTHS AND WEAKNESSES. The risk models presented in this paper are rooted in national audit (NCHDA) and national registry (ONS mortality) data, which have the strengths of being nationally representative and having their quality rigorously monitored. We defined a careful set of inclusion criteria, erring on the conservative side, to ensure that only procedures comprising core ACHD surgical practice were included. Another strength is that our model development included comorbidities and cardiac risk factors specific for adults.

The mortality outcomes are well defined for those surgeries with records linked to the ONS mortality registry or where there was NCHDA information available. A weakness is that we used the latest available life status for those surgeries having an undetermined life status at 30 or 90 days.

Another data-related weakness is that we had to exclude some centers because they did not record complications, and in other centers, there were missing values for complications (we removed those procedures). These issues, combined with some (minor) changes in some of the definitions of complications over time, make the complications outcome definition less reliable than the mortality outcomes.

Our adult survival and complications models are intended to be starting points that will be validated and refined in future using better quality data.

CONCLUSION. The risk models developed in this work will enable the reporting of mortality and complication outcomes for routine monitoring of ACHD services, taking into account differences in risk across case mix. This will allow learning from national practice and inform future quality improvement initiatives.

The adult risk models predict postsurgical 30-day and 90-day mortality well, despite a low number of events. The 30-day complications risk model performs less well, possibly because of limitations in the quality of the data collected on these outcomes and risk factors.

The authors dedicate this work to the memory of Dr Adrian Chester, who dedicated his life to promoting the field of congenital cardiac diseases and heart valve tissue engineering. He generously contributed to this research as an adult congenital heart disease patient co-applicant, sadly passing away in November 2023. The authors wish to acknowledge important initial contributions from Dr Trevor Richens on defining adult congenital heart disease practice. National Congenital Heart Disease Audit (NCHDA) data were provided by the National Institute of Cardiovascular Outcomes Research with approval from NHS England. Office for National Statistics civil registrations mortality data were provided by NHS England.

Data were held and processed in the University College London Data Safe Haven under strict governance requirements and cannot be shared with others without significant amendments to ethics, Confidentiality Advisory Group, and data sharing agreements. The R code developed for processing and analyzing linked NCHDA records is publicly available at.[15]

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DISCLOSURES

The authors have no conflicts of interest to disclose.

REFERENCES

1. Mandalenakis Z, Giang KW, Eriksson P, et al. Survival in children with congenital heart disease: have we reached a peak at 97. *J Am Heart Assoc*. 2020;9:e017704. https://doi.org/10.1161/JAHA.120.017704

2. NHS England. New Congenital Heart Disease Review: Final Report. 2015. Accessed August 28, 2025. https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf

3. National Institute of Cardiovascular Outcomes Research. National Congenital Heart Disease Audit. 2020 Summary Report (2018/19 Data). Accessed August 28, 2025. https://scts.org/_userfiles/pages/files/congential/nationalcongenitalheartdiseaseauditnchdafinal.pdf

4. Fuller SM, He X, Jacobs JP, et al. Estimating mortality risk for adult congenital heart surgery: an analysis of The Society of Thoracic

Surgeons Congenital Heart Surgery Database. *Ann Thorac Surg*. 2015;100:1728–1736. https://doi.org/10.1016/j.athoracsur.2015.07.002

5. Cho MY, Weidenbach M, Sinzobahamvya N, et al. Adult congenital open-heart surgery: emergence of a new mortality score. *Eur J Cardiothorac Surg*. 2020;58:171–176. https://doi.org/10.1093/ejcts/ezaa024

6. Constantine A, Costola G, Bianchi P, et al. Enhanced assessment of perioperative mortality risk in adults with congenital heart disease. *J Am Coll Cardiol*. 2021;78:234–242. https://doi.org/10.1016/j.jacc.2021.04.096

7. Nashef SA, Roques F, Sharples LD, et al. EuroSCORE II. *Eur J Cardiothorac Surg*. 2012;41:734–745. https://doi.org/10.1093/ejcts/ezs043

8. Nelson JS, Thibault D, O'Brien SM, et al. Development of a novel Society of Thoracic Surgeons adult congenital mortality risk model. *Ann Thorac Surg*. 2023;116:331–338. https://doi.org/10.1016/j.athoracsur.2023.01.015

9. Griffeth EM, Stephens EH, Burchill LJ, et al. Risk of cardiac reoperation: an analysis of The Society of Thoracic Surgeons Congenital Heart Surgery Database. *Ann Thorac Surg*. 2024;118:1098–1106. https://doi.org/10.1016/j.athoracsur.2024.06.013

10. Haapanen H, Tsang V, Kempny A, et al. Grown-up congenital heart surgery in 1093 consecutive cases: a "hidden" burden of early outcome. *Ann Thorac Surg*. 2020;110:1667–1676. https://doi.org/10.1016/j.athoracsur.2020.01.071

11. Collins GS, Moons KG, Dhiman P, et al. TRIPOD+AI statement: updated guidance for reporting clinical prediction models that use regression or machine learning methods. *BMJ*. 2024;385:e078378. https://doi.org/10.1136/bmj-2023-078378

12. Franklin RC, Anderson RH, Daniëls O, et al. Report of the Coding Committee of the Association for European Paediatric Cardiology. *Cardiol Young*. 2002;12:1–8. https://doi.org/10.1017/S1047951100012208

13. White O, Stickley J. National Congenital Heart Disease Audit. Data Manual for dataset version 6.1—March 25 Revision. April 2025. Accessed August 28, 2025. https://www.nicor.org.uk/~documents/data-sets/supporting-data-set-documentation/congenital-heart-disease-1/nchda-manual-v6-1-march-23-revision-23-24-final/?layout=file

14. Linked HES-ONS mortality data. NHS Digital. Accessed October 27, 2023. https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/linked-hes-ons-mortality-data

15. Espuny Pujol F, Huang Q, Stickley J, et al. UCL-CORU/CHD-research-code: LAUNCHES and CHAMPION code for analysing congenital heart disease (CHD) outcomes in the UK. 2024. Accessed August 28, 2025. https://doi.org/10.5281/zenodo.14039423

16. Hastie T, Tibshirani R, Wainwright M. *Statistical Learning with Sparsity: The Lasso and Generalizations*. Chapman and Hall/CRC; 2015.

17. Rogers L, Brown KL, Franklin RC, et al. Improving risk adjustment for mortality after pediatric cardiac surgery: the UK PRAiS2 Model. *Ann Thorac Surg*. 2017;104:211–219. https://doi.org/10.1016/j.athoracsur.2016.12.014

18. Espuny Pujol F, Franklin RC, Crowe S, et al. Transfer of congenital heart patients from paediatric to adult services in England. *Heart*. 2022;108:1964–1971. https://doi.org/10.1136/heartjnl-2022-321085

19. Brown KL, Rogers L, Barron DJ, et al. Incorporating comorbidity within risk adjustment for UK pediatric cardiac surgery. *Ann Thorac Surg*. 2017;104:220–226. https://doi.org/10.1016/j.athoracsur.2016.12.013

20. Bennett JA, Riegel B, Bittner V, et al. Validity and reliability of the NYHA classes for measuring research outcomes in patients with cardiac disease. *Heart Lung*. 2002;31:262–270. https://doi.org/10.1067/mhl.2002.124554

21. Steyerberg EW, Vickers AJ, Cook NR, et al. Assessing the performance of prediction models: a framework for traditional and novel measures. *Epidemiology*. 2010;21:128. https://doi.org/10.1097/EDE.0b013e3181c30fb2