**SECTION E: PEDIATRIC AND CONGENITAL CARDIOLOGY/CARDIOTHORACIC SURGERY**

1. **Do you have a Pediatric and Congenital Cardiology/Cardiothoracic Surgery program?**

**(HEART\_HAVEPROGRAM)**

* Yes – Go to Question E1.1
* No – Skip to Section F

**When responding to questions in this section, we recommend that you consult with the medical director of your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program(s) to ensure accurate answers that are consistent with the intent of the survey.**

**As data are reviewed, U.S. News may have questions about responses to individual questions or about an entire submission. To ensure communication with the appropriate clinical leader, please provide the following information about the chief of service (or equivalent) for your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program.**

**Full name:**

|  |
| --- |
| **(HEART\_DIR\_NAME)** |

**Title:**

|  |
| --- |
| **(HEART\_DIR\_TITLE)** |

**Email:**

|  |
| --- |
| **(HEART\_DIR\_EMAIL)** |

**Preferred phone:**

|  |
| --- |
| **(HEART\_DIR\_PHONE)** |

REQUIRED: IF NAME, TITLE, EMAIL, OR PHONE=BLANK, DISPLAY: “A response is required for [Name/Title/Email/Phone] prior to submitting the survey. Click “OK” to continue with the survey and answer this question later. Click “Cancel” to provide a response to this question now.”

**E1.1 Are you submitting jointly with a Pediatric and Congenital Cardiology/Cardiothoracic Surgery program at another hospital?**

**(HEART\_JOINTSUB)**

* + Yes – Go to Question E1.2
  + No – Skip to Question E2

**E1.2 If yes, what is the name of the Pediatric and Congenital Cardiology/Cardiothoracic Surgery program you are reportingly jointly with?** Please note that joint submissions must be reviewed and approved before they are allowed. Before submitting your survey, please contact RTI at [PediatricHospSurvey@rti.org](mailto:PediatricHospSurvey@rti.org) to discuss your joint submission request unless you already have received permission to jointly submit data in this specialty. As noted in the instructions for joint reporting, if you are granted permission, only the primary hospital in the joint reporting relationship will be allowed to report data for this specialty.

|  |
| --- |
| **(HEART\_JOINTSUB\_NAME)** |

1. **Please indicate the total number of attending/on-staff physicians (excluding fellows)[[1]](#footnote-2) who *are currently members of the medical staff* in your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program in the following categories.** [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Total Physicians** |  |
| a. | Pediatric cardiothoracic surgeons (include only board certified/board eligible by the American Board of Thoracic Surgery or equivalent for surgeons trained outside the US, with a fellowship or other training in pediatric and congenital heart surgery) **(HEART\_PHYSICIANS\_CTSURG\_** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| b. | Pediatric cardiac intensivists: Cardiologist - board certified/board eligible in Pediatrics by the American Board of Pediatrics, with subspecialty certification/eligibility in Pediatric Cardiology, plus  1 year of additional specific training in pediatric cardiac intensive care, or > 15 years of experience as a dedicated pediatric cardiac intensivist. **(HEART\_PHYSICIANS\_CARDIO\_** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| c. | Pediatric cardiac intensivists: Pediatric Critical Care - board certified/board eligible in Pediatrics by the American Board of Pediatrics, with subspecialty certification/eligibility in Pediatric Critical Care, plus 1 year of additional specific training in pediatric cardiac intensive care (additional subspecialty certification in Pediatric Cardiology satisfies this requirement), or > 15 years of experience as a dedicated pediatric cardiac intensivist. **(HEART\_PHYSICIANS\_PEDINT\_** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| d. | Pediatric cardiac intensivists: Anesthesiologist - board certified/board eligible in Anesthesia by the American Board of Anesthesia, with at least 6 months of additional training in pediatric cardiac anesthesia, and 1 year of additional training in pediatric cardiac intensive care, or > 15 years of experience as a dedicated pediatric cardiac intensivist. **(HEART\_PHYSICIANS\_ANES\_** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| e. | Pediatric cardiac interventionalists - board certified/board eligible in pediatrics by the American Board of Pediatrics, with subspecialty certification/eligibility in Pediatric Cardiology, and 1 year additional specific training in pediatric cardiac intervention, or > 15 years of experience as a dedicated pediatric cardiac interventionalist. **(HEART\_PHYSICIANS\_INTERVENT\_** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| f. | Pediatric cardiac electrophysiologists - board certified/board eligible in pediatrics by the American Board of Pediatrics, with subspecialty certification/eligibility in Pediatric Cardiology, and 1 year additional specific training in pediatric cardiac electrophysiology, or > 15 years of experience as a dedicated pediatric cardiac electrophysiologist. **(HEART\_PHYSICIANS\_ELCTRO\_** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| g. | Anesthesiologist - board certified/board eligible in Anesthesia by the American Board of Anesthesia, with at least 12 months of additional training in pediatric anesthesia or board certification/board eligible in pediatric anesthesia, and at least 6 months additional training pediatric cardiac anesthesia, or > 15 years of experience as a dedicated pediatric cardiac anesthesiologist.  **(HEART\_PHYSICIANS\_ANESTH** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| h. | Pediatric advanced imaging specialists who perform/interpret >50 pediatric cardiac MRIs and/or cardiac CT’s/year: (1) Pediatric cardiologist with extra training in advanced imaging (board certified/board eligible in pediatrics by the American Board of Pediatrics, with subspecialty certification/eligibility in pediatric cardiology) or (2) Pediatric radiologists (board certified/board-eligible by the American Board of Radiology or American Osteopathic Board of Radiology and with certification (or eligible for certification) for added qualification in pediatric radiology.) **(HEART\_PHYSICIANS\_RADIO)** | \_\_\_\_\_\_\_\_  **TOT)** |  |
| i. | Number of Cardiologists with Subspecialty Certification in Adults with Congenital Heart Disease.  **(HEART\_PHYSICIANS\_ACHD** | \_\_\_\_\_\_\_\_  **TOT)** |  |

NOTES: E2x should be whole number only. Do not allow decimals.

**E2.1 How many of the pediatric cardiothoracic surgeons listed in E2a also have obtained Subspecialty Certification in Congenital Heart Surgery from the American Board of Thoracic Surgery (ABTS)?** [If none, please enter 0.]

\_\_\_\_\_\_\_\_ Number of surgeons with subspecialty certification **(HEART\_CHS\_CERT)**

NOTES: E2.1 should be whole number only. Do not allow decimals.

***Note: The preceding questions are used to determine eligibility for Pediatric & Congenital Cardiology/Cardiothoracic Surgery. If you leave any part of these questions blank, your hospital will be considered ineligible for the rankings in Pediatric and Congenital Cardiology/Cardiothoracic Surgery.***

**E2.2 How many of the pediatric cardiothoracic surgeons listed in E2a have obtained a certification from foreign organizations (e.g., the Fellowship of the Royal Colleges of Surgeons (FRCS)), practice exclusively or primarily (greater than 90%) in congenital heart surgery and are *not* eligible for Subspecialty-Certification in Congenital Heart Surgery from the ABTS?** [If none, please enter 0.]

\_\_\_\_\_\_\_\_ Number of surgeons with foreign subspecialty certification **(HEART\_CHS\_FCERT)**

NOTES: E2.2 should be whole number only. Do not allow decimals.

1. **Does your center provide 24-hour in-house coverage every day to the cardiac-specific ICU[[2]](#footnote-3) with providers who are trained in the management of congenital heart disease and can provide immediate evaluation and intervention for critical cardiac issues, including - emergency pericardiocentesis?**

**(HEART\_ICU24)**

* Yes, in a dedicated Cardiac ICU (CICU) – Go to Question E3.1
* Yes, in a dedicated section of a Pediatric ICU (PICU) and/or Neonatal ICU (NICU) – Go to Question E3.1
* Yes, in a Pediatric ICU (PICU) and/or Neonatal ICU (NICU) without a dedicated CICU section – Go to Question E3.1
* No (none of the above) – Skip to Question E4

**E3.1 If yes to E3, which of the following in-house**[[3]](#footnote-4) **coverage options does your center provide for nights[[4]](#footnote-5) and weekends[[5]](#footnote-6)? (**Check all that apply**)**

* Attending coverage by pediatric cardiac intensivists as defined in question E2b, E2c or E2d (In order to check this box, your program must provide in-house 24/7 coverage by at least one faculty member who meet the criteria in question E2b, E2c or E2d at ALL times and that this faculty member must be dedicated only to your cardiac-specific ICU at the time of this coverage.) **(HEART\_COVERAGE\_CARDIAC)**
* Attending coverage by pediatric intensivists, who do not meet the criteria in question E2b, E2c or E2d, but regularly cover the cardiac ICU patients **(HEART\_COVERAGE\_INTENSIVISTS)**
* Pediatric cardiology, pediatric cardiac intensive care, or pediatric cardiac surgery trainees, with back-up off-site by attendings who regularly cover the cardiac ICU during the day **(HEART\_COVERAGE\_TRAINEES)**
* Non-physician advanced practice providers (APPs) who are dedicated to cardiac intensive care management, with back-up off-site by attendings who regularly cover the cardiac ICU during the day **(HEART\_COVERAGE\_APP)**
* Other staff offering coverage (please specify below) **(HEART\_COVERAGE\_OTHER)**

**E3.2 If you selected “other” in E3.1, please describe the staff that provide coverage and any off-site support that they receive from attendings or other medical staff from the cardiology and cardiothoracic surgery program at your hospital:**

|  |
| --- |
| **(HEART\_COVERAGE\_TEXT)** |

**E3.3 This question has been removed from the survey.**

1. **Please indicate the number of clinical nurse (RN), advanced registered nurse practitioner (ARNP) or advanced practice registered nurse (APRN), and Physician Assistant (PA) FTEs[[6]](#footnote-7) who work in or directly support your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program.** [Due to ongoing nursing shortages, contract nurses should be included in your counts of clinical RNs.][If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Staff FTEs** |
| a. | FTE RNs **(HEART\_FTE\_RN)** | \_\_\_\_\_\_\_\_ |
| b. | FTE ARNPs or APRNs **(HEART\_FTE\_ARNP** | \_\_\_\_\_\_\_\_ |
| c. | FTE PAs **(HEART\_FTE\_PA)** | \_\_\_\_\_\_\_\_ |

NOTES: E4x is numeric entry (decimals are allowed).

VALIDATE: If E4x is not numeric: “E4x (FTE): Please enter a numeric value.”

**E4d. What percentage of RNs working in your CICU or the dedicated Cardiac beds in the PICU have less than 2 years of cardiac critical care experience?**

\_\_\_\_\_\_\_% RNs **(HEART\_RN\_NEW)**

NOTES: E4d is numeric entry (decimals are allowed).

VALIDATE: 0 ≤ E4d ≤ 100. ELSE DISPLAY: “E4d: Please enter a numeric value between 0 and 100.”

If E24x is not numeric: “E4x: Please enter a numeric value.”

**E4e. What percentage of RNs working in your CICU or the dedicated Cardiac beds in the PICU have a BSN or higher on December 31, 2024?**

\_\_\_\_\_\_\_% RNs **(HEART\_RN\_BSN)**

NOTES: E4e is numeric entry (decimals are allowed).

VALIDATE: 0 ≤ E4e ≤ 100. ELSE DISPLAY: “E4e: Please enter a numeric value between 0 and 100.”

If E4e is not numeric: “E4e: Please enter a numeric value.”

**E4f. What percentage of eligible RNs[[7]](#footnote-8) working in your CICU or the dedicated Cardiac beds in the PICU had the CCRN certification for critical care nursing from the American Association of Critical-Care Nurses (AACN) on December 31, 2024?**

\_\_\_\_\_\_\_% RNs **(HEART\_RN\_CCRN)**

NOTES: E4f is numeric entry (decimals are allowed).

VALIDATE: 0 ≤ E4f ≤ 100. ELSE DISPLAY: “E4f: Please enter a numeric value between 0 and 100.”

If E4f is not numeric: “E4f: Please enter a numeric value.”

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program currently offer an echocardiography laboratory certified by the Intersocietal Commission for the Accreditation of Echocardiography Laboratories (ICAEL)[[8]](#footnote-9) or the American Institute of Ultrasound in Medicine (AIUM) in any of the following areas?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Transthoracic echocardiographic testing **(HEART\_ICAEL\_TRANSTHORACIC)** | ○ | ○ |
| b. | Transesophageal echocardiographic testing **(HEART\_ICAEL\_TRANSESOPHAGEAL)** | ○ | ○ |
| c. | Fetal echocardiographic testing **(HEART\_ICAEL\_FETAL)** | ○ | ○ |

**E5.1 This question has been removed from the survey.**

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program currently offer the following pediatric cardiovascular services and/or facilities on-site?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Dedicated pediatric cardiac surgical operating room(s)[[9]](#footnote-10) **(HEART\_SERVICES\_DEDICATED)** | **○** | **○** |
| b. | Cardiac intensive care unit (CICU)[[10]](#footnote-11) or dedicated beds and staff in a NICU or PICU for cardiac patients **(HEART\_SERVICES\_CICU)** | **○** | **○** |
| c. | Remote monitoring capability of cardiac patients in the CICU, NICU, or PICU[[11]](#footnote-12) **(HEART\_SERVICES\_REMOTE)** | **○** | **○** |
| d. | Ventricular assist program[[12]](#footnote-13) **(HEART\_SERVICES\_VAP)** | **○** | **○** |
| e. | Cardiovascular genetics clinic[[13]](#footnote-14) **(HEART\_SERVICES\_GENETICS)** | **○** | **○** |

1. **This question has been removed from the survey.**
2. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program routinely track data about cardiac catheterization and submit these cardiac catheterization data to a national registry – NCDR IMPACT, C3PO or CCISC?**

**(HEART\_NCDR)**

* Yes – Go to E9
* No – Skip to E12

1. **This question has been removed from the survey.**
2. **This question has been removed from the survey.**

**Note that we have removed question E11 from this year’s survey. Previously, question E11 captured the data based on the NCDR IMPACT registry, while E12 captured the same information but from EMR, catheterization lab, or other record systems within the hospital. This year, we are no longer requesting data based on the NCDR IMPACT registry in E11 but would still request that hospitals use the NCDR IMPACT definitions when responding to E12 regarding catheter procedure volumes.**

1. **This question has been removed from the survey.**
2. **Using data from your Cath Lab records, how many cardiac catheterization cases were performed in each of the categories listed below by your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program at your hospital[[14]](#footnote-15) from July 1, 2023 to June 30, 2024?** [Please note that hospitals not participating in IMPACT must follow IMPACT definitions when answering this question.See code lists and use the following rules. Count only one case for each catheterization, regardless of the number of procedures performed. For example, if a diagnostic case, a biopsy, and an intervention were performed during the same case, the count would only be 1. In the methodology below, interventions are the remainder after all other counts, so if a biopsy or ablation is performed with a significant intervention and your hospital prefers to count the intervention, you should subtract the case from the biopsy or ablation list. The code lists will not identify this uncommon situation for you.]

**Please note that E12c will not be used for scoring. It is being asked specifically to allow calculation of E12e. Clicking "save" will calculate the value for E12e by taking the total from E12a and subtracting (E12b+E12c+E12d)."**

|  |  |  |
| --- | --- | --- |
|  |  | **Cases** |
| a. | Total number of catheterization lab visits (see code list)[[15]](#footnote-16)  **(HEART\_CATH\_nNCDR\_** | **VISITS)** |
| b. | Diagnostic catheterization only (hemodynamic and/or angiographic evaluation) (see code list)[[16]](#footnote-17)  **(HEART\_CATH\_nNCDR\_** | **DIAG)** |
| c. | Endomyocardial biopsy <18 years of age (with or without a diagnostic procedure, and without an additional intervention) (see code list)  **(HEART\_CATH\_nNCDR\_** | **BIOP)** |
| d. | Electrophysiology Procedures (see code list, for patients >18 years of age only count if congenital heart disease)  **(HEART\_CATH\_nNCDR\_** | **ABLATION)** |
| e. | Interventional procedure (with or without a diagnostic procedure or biopsy) **(HEART\_CATH\_nNCDR\_INTERVEN)** | **AUTOCALC: E12e=E12a-(E12b+E12c+E12d)** |
| f. | Transcatheter Pulmonary Valve Replacements (see code list)  **(HEART\_CATH\_nNCDR\_** | **REPLACE)** |

NOTES: E12x should be whole number only. Do not allow decimals.

WARNING: IF E12b + E12c + E12d > E12a, DISPLAY: “The number of catheterization lab visits in E12b-E12e must equal the total number of catheterization lab visits (E12a).”

AUTOCALC: E12e = E12a – (E12b + E12c + E12d).

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program conduct Transcatheter Aortic Valve Replacement (TAVR)?** [Please count replacements conducted on site at your hospital, off site at a single affiliated hospital, or both on site at your hospital and off site at a single affiliated hospital.]

**(HEART\_TAVR)**

* Yes
* No

1. **This question has been removed from the survey.**

**E14.1 How many catheter ablations (cryoablation and radiofrequency—see code list) were conducted by your Pediatric Congenital Cardiology/Cardiothoracic Survey program in the last calendar year?** [If none, please enter 0.]

\_\_\_\_\_\_\_\_ Number of catheter ablations **(HEART\_CATHABS\_TOT)**

NOTES: E14.1 should be whole number only. Do not allow decimals.

1. **How many procedures for implantation, removal, extraction, repair, or replacement of a permanent transvenous device used for pacing, cardioversion, or defibrillation (see code list) were performed by an electrophysiologist in the catheterization laboratory or the OR during the last calendar year?** [Count only one procedure per patient day when calculating your total, and do not count procedures performed by a surgeon since they are separately counted in E38.] [If none, please enter 0.]

\_\_\_\_\_\_\_\_ Number of procedures **(HEART\_PACING\_PROCS)**

NOTES: E15 should be whole number only. Do not allow decimals.

**E15.1.** **Has your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program performed lead extraction for pacemaker or automatic implantable cardioverter defibrillator (ICD / AICD) leads in the last calendar year (2024), either on site at your hospital or off site at a SINGLE affiliated hospital (or both onsite at your hospital and off site at SINGLE affiliated hospital)?**

**(HEART\_LEAD\_EXTRACT)**

* Yes
* No

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program have an organized *adult* congenital heart program[[17]](#footnote-18) for patients > 18 years of age?**

**(HEART\_CONGENITAL)**

* Yes – on site at your hospital, go to Question E17
* Yes – off site at a single affiliated hospital, go to Question E16.1 (If at multiple affiliated sites, must answer no.)
* No – Skip to Question E18

**E16.1 If you answered “Yes – off site at a single affiliated hospital” please specify the name of the hospital below. Note that this question must be answered to receive credit.**

|  |
| --- |
| **(HEART\_ADULT\_AFFILIATE)** |

1. **Does your pediatric and congenital cardiology/cardiothoracic surgery program provide the following?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | A formal transition program[[18]](#footnote-19) to actively transition patients from the pediatric to adult congenital heart program. **(HEART\_CONGENITAL\_TRANSITION)** | ○ | ○ |
| b. | Cardiothoracic surgeons in your program for ***adults with congenital heart disease*** who have specialty expertise in the care of adults with congenital heart disease (Only check yes if the surgeon/s either have subspecialty certification in Congenital Heart Surgery Board or have >10 years of experience with at least 50% of their practice in congenital heart surgery.). **(HEART\_CONGENITAL\_SURGEONS)** | ○ | ○ |
| c. | Cardiothoracic interventionalists in your program for ***adults with congenital heart disease*** who have specialty expertise in the care of adults with congenital heart disease (Only check yes if the interventionalist(s) either meet the criteria in Question E2e or have >10 years of experience with at least 50% of their practice in congenital heart interventions.). **(HEART\_CONGENITAL\_INTERVENT)** | ○ | ○ |
| d. | Cardiothoracic electrophysiologists in your program for ***adults with congenital heart disease*** who have specialty expertise in the care of adults with congenital heart disease (Only check yes if the electrophysiologist/s either meet the criteria in Question E2f or have >10 years of experience with at least 25% of their practice in congenital heart electrophysiology.). **(HEART\_CONGENITAL\_ELECTROPHYS)** | ○ | ○ |
| e. | Specialty care for high risk obstetrics for patients with congenital heart disease. **(HEART\_CONGENITAL\_OBSTETRICS)** | ○ | ○ |
| f. | Pediatric or adult cardiologist, who is board certified in cardiology and in the maintenance of certification (MOC) program for Adult Congenital Heart Disease by the American Board of Internal Medicine. **(HEART\_CONGENITAL\_MOC)** | ○ | ○ |

1. **Please indicate which of the following mechanisms you will use for reporting volume and outcomes on your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program for each of the 4 calendar years listed below. For relevant volume and mortality questions that follow in this section, the same 4 years July 1, 2020 through June 30, 2024 will be used for all data reporting. If your center is using information from the STS Congenital Heart Surgery Database reports for volume and mortality, the relevant tables specified in footnotes[[19]](#footnote-20) and*must be submitted to receive credit*.**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **STS CHSD report** | **Other Data Source** |
| a. | Reporting year 1 (July 2020 – June 2021) **(HEART\_STS\_YR1)** | ○ | ○ |
| b. | Reporting year 2 (July 2021 – June 2022) **(HEART\_STS\_YR2)** | ○ | ○ |
| c. | Reporting year 3 (July 2022 – June 2023) **(HEART\_STS\_YR3)** | ○ | ○ |
| d. | Reporting year 4 (July 2023 – June 2024) **(HEART\_STS\_YR4)** | ○ | ○ |

**E18.1 If you participate in the STS Congenital Heart Surgery Database, please provide the name of the organization you are listed under in the database.**

|  |
| --- |
| **(HEART\_STSNAME)** |

**E18.2 If you will be using data “other” than from the STS Congenital Heart Surgery Database for reporting (e.g., combination of STS and some other source, another database used to track cardiothoracic surgeries, or manual review of charts), please indicate the source below for each reporting year.**

|  |
| --- |
| **(HEART\_SOURCE)** |

**E18.3 Does data from your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program actually appear on the STS Public Reporting On-Line program from operations performed at your institution in January 2020 to December 2023?[[20]](#footnote-21)**

**(HEART\_STS\_PUBLIC)**

* Yes
* No

1. **What was the total number of adult cardiac surgical operations listed in Table 7 (operations in analyses) of your STS Congenital Heart Surgery Database Report for the 4 reporting years, July 2020 through June 2024?** [For hospitals not reporting STS data, please exclude all secundum ASD’s (see code list for exclusions), any surgery limited to the mitral or aortic valves, and coronary bypass grafting. Also, you must count each operative encounter as a single case, even if multiple procedures were performed during the same operative episode.] [If none, please enter 0.]

\_\_\_\_\_\_\_\_ Number of adult cardiac surgical operations **(HEART\_SURG\_PROCS)**

NOTES: E19 should be whole number only. Do not allow decimals.

1. **Does your *adult* congenital heart program have full accreditation as an Adult Congenital Heart Association Comprehensive Care Center (**[**www.achaheart.org**](http://www.achaheart.org/)**)?**

**(HEART\_ACHA)**

* Yes, full accreditation
* No

**E20.1 What was the total number of neonatal cardiac surgical operations listed in Table 7 (operations in analyses) of your STS Congenital Heart Surgery Database Report for the 4 reporting years, July 2020 through June 2024?** [For hospitals not reporting STS data, how many neonatal cardiac surgical operations were performed on patients <31 days of age (preterm and full term) (see code list) in the 4 reporting years, July 2020 through June 2024?Also, you must counteach operative encounter as a single case, even if multiple procedures were performed during the same operative episode.] [If none, please enter 0.]

\_\_\_\_\_\_\_ Number of neonatal cardiac operations **(HEART\_NEO\_CARDSURG)**

NOTES: E20.1 should be whole number only. Do not allow decimals.

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program have an on-site heart or heart-lung transplant program recognized by the United Network for Organ Sharing (UNOS)?**

**(HEART\_UNOS)**

* Yes – Go to Question E22
* No – Skip to Question E26

1. **How many unique patients (<18 years of age) received heart transplants in your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program in the 4 reporting years, July 2020 through June 2024?** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Unique Patients** |
| a. | Reporting year 1 (July 2020 – June 2021) **(HEART\_TRANSPLANTS\_YR1)** | \_\_\_\_\_\_\_\_ |
| b. | Reporting year 2 (July 2021 – June 2022) **(HEART\_TRANSPLANTS\_YR2)** | \_\_\_\_\_\_\_\_ |
| c. | Reporting year 3 (July 2022 – June 2023) **(HEART\_TRANSPLANTS\_YR3** | \_\_\_\_\_\_\_\_ |
| d. | Reporting year 4 (July 2023 – June 2024) **(HEART\_TRANSPLANTS\_YR4)** | \_\_\_\_\_\_\_\_ |

NOTES: E22x should be whole number only. Do not allow decimals.

**E22.1 How many of the unique patients in E22 were <1 year of age when they received heart transplants in your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program in the 4 reporting years, July 2020 through June 2024?** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Unique Patients** |
| a. | Reporting year 1 (July 2020 – June 2021) **(HEART\_TRANSPLANTS\_YR1\_AGE1)** | \_\_\_\_\_\_\_\_ |
| b. | Reporting year 2 (July 2021 – June 2022) **(HEART\_TRANSPLANTS\_YR2\_AGE1)** | \_\_\_\_\_\_\_\_ |
| c. | Reporting year 3 (July 2022 – June 2023) **(HEART\_TRANSPLANTS\_YR3\_AGE1)** | \_\_\_\_\_\_\_\_ |
| d. | Reporting year 4 (July 2023 – June 2024) **(HEART\_TRANSPLANTS\_YR4\_AGE1)** | \_\_\_\_\_\_\_\_ |

NOTES: E22.1x should be whole number only. Do not allow decimals.

VALIDATE: IF E22.1x > E22x, DISPLAY: “E22.1x: The number of patients who were <1 year of age when they received heart transplants (E22.1) should be less than or equal to the total number of patients who received heart transplants (E22).”

1. **Please report your program’s Pediatric (<18) 1-year heart transplant patient survival statistics from Table C19D in your December SRTR report, which includes transplants performed between July 1, 2021 and December 31, 2023.** [Please refer to tables C19D and C20D of the PDF version of the December 2024 SRTR report for your center for the requested values. If any elements of the table from SRTR are blank or listed as N/A, please leave them blank.]

|  |  |  |
| --- | --- | --- |
|  | **1-year SRTR Measure** | **Table C19D Value** |
|  | Number of transplants evaluated (**HEART\_SRTR\_1PATS)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | Estimated probability of surviving at 1 year (unadjusted) (**HEART\_SRTR\_1ESTUN)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_%** |
|  | Expected probability of surviving at 1 year (adjusted) (**HEART\_SRTR\_1ESTAD)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_%** |
|  | Number of observed deaths during the first year after transplant (**HEART\_SRTR\_1OBS)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | Number of expected deaths during the first year after transplant (**HEART\_SRTR\_1EXP)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | Estimated hazard ratio **(HEART\_SRTR\_1YR)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | 95% credible interval (low value) (**HEART\_SRTR\_1LOW)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | 95% credible interval (high value) (**HEART\_SRTR\_1HIGH)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |

NOTES: E23a should be whole number only. Do not allow decimals.

E23b-h is numeric entry (decimals are allowed). Allow up to 4 decimals.

VALIDATE: IF E23d > E23a, DISPLAY: “Number of observed deaths during the first year after transplant (E23d) cannot be greater than number of transplants evaluated (E23a).”

IF E23g > E23h, DISPLAY: “Please check your credible interval bounds as the upper interval limit should be greater than the lower interval limit.”

If E23b is not numeric: “E23b: Please enter a numeric value.”

If E23c is not numeric: “E23c: Please enter a numeric value.”

If E23d is not numeric: “E23d: Please enter a numeric value.”

If E23e is not numeric: “E23e: Please enter a numeric value.”

If E23f is not numeric: “E23f: Please enter a numeric value.”

If E23g is not numeric: “E23g: Please enter a numeric value.”

If E23h is not numeric: “E23h: Please enter a numeric value.”

1. **Please report your program’s Pediatric (<18) 3-year heart transplant patient survival statistics from Table C20D in your December SRTR report, which includes transplants performed between January 1, 2019 and June 30, 2021.** [If any elements of the table from SRTR are blank or listed as N/A, please leave them blank.]

|  |  |  |
| --- | --- | --- |
|  | **3-year SRTR Measure** | **Table C20D Value** |
|  | Number of transplants evaluated (**HEART\_SRTR\_3PATS)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | Estimated probability of surviving at 3 years (unadjusted) (**HEART\_SRTR\_3ESTUN)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_%** |
|  | Expected probability of surviving at 3 years (adjusted) (**HEART\_SRTR\_3ESTAD)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_%** |
|  | Number of observed deaths during the first 3 years after transplant (**HEART\_SRTR\_3OBS)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | Number of expected deaths during the first 3 years after transplant (**HEART\_SRTR\_3EXP)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | Estimated hazard ratio **(HEART\_SRTR\_3YR)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | 95% credible interval (low value) (**HEART\_SRTR\_3LOW)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |
|  | 95% credible interval (high value) (**HEART\_SRTR\_3HIGH)** | **\_\_\_\_\_\_\_\_\_\_\_\_\_\_** |

NOTES: E24a should be whole number only. Do not allow decimals.

E24b-h is numeric entry (decimals are allowed). Allow up to 4 decimals.

VALIDATE: IF E24d > E24a, DISPLAY: “Number of observed deaths during the first 3 years after transplant (E24d) cannot be greater than number of transplants evaluated (E24a).”

IF E24g > E24h, DISPLAY: “Please check your credible interval bounds as the upper interval limit should be greater than the lower interval limit.”

If E24b is not numeric: “E24b: Please enter a numeric value.”

If E24c is not numeric: “E24c: Please enter a numeric value.”

If E24d is not numeric: “E24d: Please enter a numeric value.”

If E24e is not numeric: “E24e: Please enter a numeric value.”

If E24f is not numeric: “E24f: Please enter a numeric value.”

If E24g is not numeric: “E24g: Please enter a numeric value.”

If E24h is not numeric: “E24h: Please enter a numeric value.”

**E24.1 Please list the name your hospital reports under to SRTR. Also, please note that we will verify[[21]](#footnote-22) the values reported with the SRTR/UNOS reports for your hospital. If the SRTR/UNOS values differ from the values reported here, please provide an explanation:**

|  |
| --- |
| **(HEART\_SURVIVALRATE\_TEXT)** |

1. **Please answer the following questions about the heart transplants offered by your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program.**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Has your pediatric heart transplant program performed cardiac transplantation in a recipient with high (≥ 10%) panel reactive antibody (PRA) in the last 48 months (January 2021 – December 2024)? **(HEART\_PRA\_TRANS)** | ○ | ○ |
| b. | Has your pediatric heart transplant program performed an ABO incompatible heart transplant in the last 48 months (January 2021 – December 2024)? **(HEART\_ABO\_TRANS)** | ○ | ○ |

1. **How many unique patients in the following age groups were treated with a Berlin heart or other Ventricular Assist Device (VAD), excluding ECMO (see code list), in the last 4 reporting years, July 2020 through June 2024? For the purposes of this question, please do not count transcatheter VADs.** [If none, please enter 0.]

\_\_\_\_\_\_\_\_ a. Uniquepatients (< 1 years of age) **(HEART\_BERLIN1)**

\_\_\_\_\_\_\_\_ b. Uniquepatients (>1 and < 3 years of age) **(HEART\_BERLIN3)**

\_\_\_\_\_\_\_\_ c. Uniquepatients (≥3 and <10 years of age) **(HEART\_BERLIN10)**

\_\_\_\_\_\_\_\_ d. Uniquepatients (≥10 and <18 years of age) **(HEART\_BERLIN18)**

\_\_\_\_\_\_\_\_ e. Uniquepatients (>18 years of age with congenital heart disease[[22]](#footnote-23)) **(HEART\_BERLIN19)**

NOTES: E26x should be whole number only. Do not allow decimals.

**E26.1 Has your program placed a transcatheter VAD in the last year July 2023 through June 2024?**

**(HEART\_TRANSCATHETER\_VAD)**

* Yes
* No

1. **This question has been removed from the survey.**

**E27.1** **Does your pediatric and congenital cardiology/cardiothoracic surgery program offer the following pediatric cardiology programs with a nursing and/or administrative coordinator:**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Active home surveillance program[[23]](#footnote-24)  **(HEART\_PROGM\_SURV)** | **○** | **○** |
| b. | Neurodevelopmental follow up program[[24]](#footnote-25)  **(HEART\_PROGM\_NEURO­\_FU)** | **○** | **○** |
| c. | Fontan follow up program[[25]](#footnote-26)  **(HEART\_PROGM\_FONTAN)** | **○** | **○** |
| d. | Fetal cardiology program[[26]](#footnote-27)  **(HEART\_PROGM\_FETAL\_CARD)** | **○** | **○** |
| e. | Pulmonary hypertension program[[27]](#footnote-28)  **(HEART\_PROGM\_PULM\_HYPER)** | **○** | **○** |
| f. | **N**euromuscular program[[28]](#footnote-29)  **(HEART\_PROGM\_NEUROMUSC)** | **○** | **○** |
| g. | Aortopathy program[[29]](#footnote-30)  **(HEART\_PROGM\_AORTOP)** | **○** | **○** |
| h. | Preventive cardiology program[[30]](#footnote-31)  **(HEART\_PROGM\_PREV\_CARD)** | **○** | **○** |
| i. | Heart failure/transplant clinic[[31]](#footnote-32)  **(HEART\_PROGM\_TRANSPL)** | **○** | **○** |

1. **This question has been removed from the survey.**

**E28.1 This question has been removed from the survey.**

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program currently participate and contribute data (if applicable) to any of the following?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Society of Thoracic Surgeons (STS) Congenital Heart Surgery Database and submit data for all STS indexed cardiac operations [Credit will only be given if a mortality report (see E18) is submitted in this survey] **(HEART\_DATA\_STS)** | **○** | **○** |
| b. | Congenital Heart Surgeons’ Society data center and submit data for at least 50% of the patients eligible for CHSS studies **(HEART\_DATA\_CHSS)** | **○** | **○** |
| c. | National Pediatric Cardiology – Quality Improvement Collaborative (NPC-QIC) and submit data for all eligible cases **(HEART\_DATA\_NPCQIC)** | ○ | ○ |
| d. | Congenital Cardiac Anesthesia Society database and submit data for all STS indexed cardiac operations **(HEART\_DATA\_CCISC)** | ○ | ○ |
| e. | Extracorporeal Life Support Organization (ELSO) registry and submit data for all eligible cardiac ECMO cases **(HEART\_DATA\_ELSO)** | **○** | **○** |
| f. | Pediatric Cardiac Critical Care Consortium (PC4) or Virtual pediatric ICU System (VPS) and submit data for all eligible cases **(HEART\_DATA\_PC4)** | **○** | **○** |
| g. | Pediatric Heart Transplant Study (PHTS) and submit data for all eligible cases **(HEART\_DATA\_PHTS)** | **○** | **○** |
| h. | Cardiac Neurodevelopmental Outcome Collaborative (CNOC)(participation only) **(HEART\_DATA\_CNOC)** | **○** | **○** |
| i. | Pediatric Acute Care Cardiology Collaborative (PAC3) **(HEART\_DATA\_PAC3)** | **○** | **○** |
| j. | Pedimacs Registry (FDA Database for Ventricular Assist Devices) “and/or” ACTION [<https://www.actionlearningnetwork.org/>] **(HEART\_DATA\_PEDIMAX)** | **○** | **○** |
| k. | NCDR ACC QNET program(participation only) **(HEART\_DATA\_QNET)** | **○** | **○** |
| l. | Fetal Heart Society **(HEART\_DATA\_FHSOCIETY)** | **○** | **○** |
| m. | Fontan Outcome Network **(HEART\_DATA\_FONETWORK)** | **○** | **○** |
| n. | The Consortium of Congenital Cardiac Care-Measurement of Nursing Practice (C4-MNP) **(HEART\_DATA\_CONSORTIUM)** | **○** | **○** |
| o. | Other externally audited, national quality-improvement initiative that you submit data for at least 75% of eligible cases **(HEART\_DATA\_OTH)** | **○** | **○** |

SKIP LOGIC: IF E29o=YES, GO TO E29.1. ELSE, GO TO E30.

**E29.1 If “yes” to E29o, please list:**

|  |
| --- |
| **(HEART\_DATA\_TEXT)** |

1. **Does your Cardiology/Cardiothoracic Surgery program currently participate in one or more the following types of investigative work?** [To answer yes to any of the following, your program must have had at least one patient enrolled in calendar year 2024, or subjects enrolled prior to 2024 who were in the follow-up phase during 2024.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Single institution retrospective studies and multi-institutional respective studies **(HEART\_STUDY\_INST)** | **○** | **○** |
| b. | Basic science, with extramural funding **(HEART\_STUDY\_BASIC)** | ○ | ○ |
| c. | Prospective clinical studies or trials[[32]](#footnote-33), with industry funding **(HEART\_STUDY\_INDUSTRY)** | ○ | ○ |
| d. | Prospective clinical studies or trials[[33]](#footnote-34), with competitive extramural funding**(HEART\_STUDY\_EXTRAMURAL)** | ○ | ○ |

1. **Prior to cardiac surgical procedures, does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program engage in the following surgical site infection prevention procedures?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Pre-operative bath (bathing with soap and water, chlorhexidine-containing solution, or wiping with chlorhexidine-impregnated cloth prior to surgery) **(HEART\_PREV\_BATH)** | **○** | **○** |
| b. | No use of a razor for hair removal (clipper or other non-traumatic method allowed) **(HEART\_PREV\_CLIPPER)** | **○** | **○** |
| c. | Preparation of skin at surgical site with alcohol containing agent (if no contraindications) **(HEART\_PREV\_ALCOHOL)** | ○ | ○ |
| d. | Screen for and appropriately decolonize Staph. Aureus colonized patients utilizing a nasal antiseptic **(HEART\_PREV\_STAPH)** | ○ | ○ |

1. **This question has been removed from the survey.**
2. **This question has been removed from the survey.**
3. **What was your percentage of cardiac cases developing SSIs (see code list) after cardiac surgery in 2023?** [Calculate as follows: (1) Determine the number of SSIs developing after cardiac surgery. (2) Determine the number of cardiac surgeries. (3) Clicking “Save” will calculate the rate by dividing the number of cases developing SSIs by the number of eligible cardiac surgeries, multiplied by 100.]

\_\_\_\_\_\_\_\_ a. Number of cases developing SSIs **(HEART\_SSI\_CASES)**

\_\_\_\_\_\_\_\_ b. Number of eligible cardiac surgeries **(HEART\_SSI\_TOTAL)**

\_\_\_\_\_\_\_\_ c. SSI rate **(HEART\_SSI\_PCT)**

NOTES: E34a and E34b should be whole number only. Do not allow decimals.

E34c is numeric entry (decimals are allowed).

VALIDATE: IF E34a > E34b, DISPLAY: “E34: Please check your responses. Number of cases developing SSIs cannot be greater than number of cases.”

AUTOCALC: E34c = [(E34a / E34b) \*100]

**E34.1 What source of data do you use to determine the number of cases developing SSIs?** [Check all that apply]

* NHSN/CDC standards **(HEART\_SSI\_NOM\_NHSN)**
* STS standards **(HEART\_SSI\_NOM\_STS)**

**E34.2 This question has been removed from the survey.**

**E34.3 What source of data do you use to determine the number of eligible cardiac surgeries for your SSI rate?**

* NHSN/CDC standards **(HEART\_SSI\_DENOM\_NHSN)**
* STS standards **(HEART\_SSI\_DENOM\_STS)**

**E34.4 This question has been removed from the survey.**

**E34.5 Does your hospital’s 2023 NHSN report include a standardized infection ratio (SIR) for SSIs following cardiac surgery?**

**(HEART\_SIR\_REPORT)**

* + Yes – Go to Question E34.6
  + No – Go to Question E35

**E34.6 Please report your NHSN-generated SSI standardized infection ratio (SIR), SIR p-value, and 95% confidence intervals (CI) in 2023 for your cardiac surgery program.** This information is readily available for facilities reporting SSI data to NHSN. Regenerate datasets in NHSN before running the report[[34]](#footnote-35) in NHSN Analysis. [Please note that all hospitals wishing to receive credit for this question will be required to upload a screenshot of their NHSN report with the SIR information when submitting their survey.]

\_\_\_\_\_\_\_\_\_a. Predicted SSI events (numPred) **(HEART\_SSI\_SIR\_EVENTS)**

\_\_\_\_\_\_\_\_\_b. SSI SIR (SIR) **(HEART\_SSI\_SIR)**

\_\_\_\_\_\_\_\_\_c. SIR p-value (SIR\_pval) **(HEART\_SSI\_PVALUE)**

\_\_\_\_\_\_\_\_\_d. 95% confidence interval lower (sir95ci) **(HEART\_SSI\_INTERVALL)**

\_\_\_\_\_\_\_\_\_e. 95% confidence interval upper (sir95ci) **(HEART\_SSI\_INTERVALU)**

NOTES: E34.6x is numeric entry (decimals are allowed).

VALIDATE: IF E34.6e < E34.6d DISPLAY: “E34.6d & E34.6e: Please check your confidence interval bounds as the upper interval limit should be greater than the lower interval limit.”

IF E34.6b > E34.6e OR E34.6b < E34.6d DISPLAY, “E34.6b: The SSI SIR estimate should be between the two confidence interval bounds. Please double check your responses.”

If E34.6x is not numeric: “E34.6x: Please enter a numeric value.”

1. **This question has been removed from the survey.**

**E35.1 This question has been removed from the survey.**

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program use Clinical Practice Guidelines[[35]](#footnote-36) for peri-operative and post-operative care for the following patient groups/care?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Single ventricle/shunt management (e.g. – Norwood, BTS, Glenn, Fontan) **(HEART\_CPC\_SINGLE)** | **○** | **○** |
| b. | Two ventricle repairs (e.g. – VSD, TOF, d-TGA/ASO) **(HEART\_CPC\_TWO)** | **○** | **○** |
| c. | Infant feeding (may be part of a. or b.) **(HEART\_CPC\_INFANT)** | ○ | ○ |
| d. | Anticoagulation **(HEART\_CPC\_ANTI)** | ○ | ○ |
| e. | Sedation and pain management (**HEART\_CPC\_SED)** | ○ | ○ |

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program routinely track and submit EVERY occurrence of the following surgical complications to the STS Congenital Heart Database? (DO NOT answer YES unless the data for all operations are submitted to STS.)**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Unplanned reoperation or intervention[[36]](#footnote-37) during the same hospital admission as the primary surgery **(HEART\_TRACK\_REOP)** | **○** | **○** |
| b. | Re-exploration for bleeding[[37]](#footnote-38) **(HEART\_TRACK\_REEX)** | **○** | **○** |
| c. | Deep sternal wound infection/mediastinitis[[38]](#footnote-39) **(HEART\_TRACK\_DEEP)** | ○ | ○ |
| d. | Arrhythmia necessitating temporary and permanent pacemakers[[39]](#footnote-40) (STS Versions 3.0, 3.22, 3.3, and 3.41) **(HEART\_TRACK\_ATRIO)** | ○ | ○ |
| e. | Postop mechanical circulatory support **(HEART\_TRACK\_CIRC)** | ○ | ○ |
| f. | Postop renal failure **(HEART\_TRACK\_RENAL)** | ○ | ○ |
| g. | Stroke **(HEART\_TRACK\_STROKE)** | ○ | ○ |

**E37.1. What was the total number (cumulative incidence) of patients who underwent Complete AV Canal repair in the last 4 reporting years, July 2020 through June 2024, and the total number of these patients who underwent an unplanned cardiac reoperation, prior to discharge from the hospitalization of their surgical repair?** [Please refer to and submit Table 25 (AV Canal (AVC) Defect, Last 4 Years) (July 2020 – June 2024)) from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024]. [If none, please enter 0.]

\_\_\_\_\_\_\_\_a. Total number of patients[[40]](#footnote-41) who underwent complete AV Canal repair (as listed in Table 25: July 2020 – June 2024) **(HEART\_AVCANAL\_REP)**

\_\_\_\_\_\_\_\_b. Total number of patients[[41]](#footnote-42) that underwent an Unplanned Cardiac Reoperation following complete AV Canal repair, prior to discharge from the hospitalization of their surgical repair **(**as listed in Table 25: July 2020 – June 2024) **(HEART\_AVCANAL\_REOP)**

NOTES: E37.1x should be whole number only. Do not allow decimals.

VALIDATE: If E37.1b>E37.1a, DISPLAY, “E37.1: Please check your responses. Number of patients that required an unplanned cardiac reoperation cannot be greater than the number of patients who underwent AV Canal repair.”

IF E37.1x IS BLANK, DISPLAY: “E37.1x: If none, please enter 0.”

**E37.2. This question has been removed from the survey.**

**E37.3. What was the total number (cumulative incidence) of patients who underwent Arterial Switch Operations for Transposition of the Great Arteries with intact ventricular septum (TGA, IVS) in the last 4 reporting years, July 2020 through June 2024 and the total number of these patients who were managed with postoperative Mechanical Circulatory Support following Arterial Switch Operations for TGA, IVS?** [Please refer to and submit Table 27 (Transposition of the Great Arteries, Last 4 Years (July 2020 – June 2024)) from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024]. [If none, please enter 0.]

\_\_\_\_\_\_\_\_a. Total number of patients who underwent Arterial Switch Operations for Transposition of the Great Arteries with intact ventricular septum (sum of TGA, IVS + Switch) (as listed in Table 27: July 2020 – June 2024) **(HEART\_TGA\_CUMMULATIVE)**

\_\_\_\_\_\_\_\_b. Total number of patients managed with postoperative Mechanical Circulatory Support following Transposition of the Great Arteries with intact ventricular septum (sum of TGA, IVS + Switch) (as listed in Table 27: July 2020 – June 2024) **(HEART\_TGA\_NUMBER)**

NOTES: E37.3x should be whole number only. Do not allow decimals.

VALIDATE: If E37.3b>E37.3a, DISPLAY, “E37.3: Please check your responses. Number of patients with postoperative support cannot be greater than the number of patients who underwent arterial switch operations.”

IF E37.3x IS BLANK, DISPLAY: “E37.3x: If none, please enter 0.”

SKIP LOGIC: IF E37d=Yes, GO TO E37.4; ELSE SKIP TO E37.5.

**E37.4. If yes to E37d, what was the total number (cumulative incidence) of patients who underwent VSD repair in the last 4 reporting years, July 2020 through June 2024 and total number of these patients that developed “Arrhythmia req. Permanent Pacemaker” following VSD repair?** [Please refer to and submit Table 21 (Ventricular Septal Defect, Last 4 Years (July 2020 – June 2024))from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024]. [If none, please enter 0.]

\_\_\_\_\_\_\_\_a. Total number of patients who underwent VSD repair (as listed in Table 21: July 2020 – June 2024) **(HEART\_VSD\_CUMMULATIVE)**

\_\_\_\_\_\_\_\_b. Total number of patients that developed “Arrhythmia req. Permanent Pacemaker” following VSD repair (as listed in Table 21: July 2020 – June 2024) **(HEART\_VSD\_NUMBER)**

NOTES: E37.4x should be whole number only. Do not allow decimals.

VALIDATE: If E37.4b>E37.4a, DISPLAY, “E37.4: Please check your responses. Number of patients that developed arrhythmia cannot be greater than the number of patients who underwent VSD repair.”

IF E37.4x IS BLANK, DISPLAY: “E37.4x: If none, please enter 0.”

**E37.5. What was the 4-year combined Risk-Adjusted Operative Mortality for your Pediatric and Congenital Cardiology and Cardiothoracic Surgery program for NEONATES and INFANTS only in each of the following STAT Mortality Categories?** [Please refer to Table 16 from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024 for data from the time period of July 1, 2020 through June 30, 2024, inclusive. For the combined reporting years, as indicated in E18, please provide the “# Eligible” (volume) and adjusted mortality rate (AMR) from the section titled “Neonates + Infants” for each individual STAT Mortality Category. [Please leave this question blank if your program did not receive adjusted mortality rates in Table 16.]

* N/A, our program does not have an AMR value for this measure – Skip to E37.6 **(HEART\_STATi\_NA)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **STAT Level** | **# Eligible**  **(Volume) for neonates and infants only** | **4-year combined AMR for neonates and infants** | **Lower limit of the AMR**  **confidence interval for neonates and infants** | **Upper limit of the AMR**  **confidence interval for neonates and infants** |
| a. | STAT Level 1 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT1i** | **\_VOL)** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| b. | STAT Level 2 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT2i** | **\_VOL)** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| c. | STAT Level 3 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT3i** | **\_VOL)** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| d. | STAT Level 4 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT4i** | **\_VOL)** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| e. | STAT Level 5 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT5i** | **\_VOL)** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |

NOTES: E37.5x1 should be whole number only. Do not allow decimals.

E37.5x2, E37.5x3, and E37.5x4 is numeric entry (decimals are allowed).

N/A should be mutually exclusive (i.e. cannot be selected with other responses).

VALIDATE: If E37.5x3 > E37.5x4, DISPLAY: “E37.5x: Please check your responses. The upper limit of the confidence interval should be larger than the lower limit number of the confidence interval.”

If E37.5x3 > E37.5x2, DISPLAY: “E37.5x: Please check your responses. The AMR value should be larger than the lower limit number of the confidence interval.”

If E37.5x2 > E37.5x4, DISPLAY: “E37.5x: Please check your responses. The AMR value should be lower than the upper limit number of the confidence interval.”

If E37.5x2, is not numeric: “E37.5x2: Please enter a numeric value.”

If E37.5x3, is not numeric: “E37.5x3: Please enter a numeric value.”

If E37.5x4, is not numeric: “E37.5x4: Please enter a numeric value.”

SKIP LOGIC: IF E37.5 IS N/A (HEART\_STATi\_NA=1), GO TO E37.6; ELSE SKIP TO E38.

**E37.6.** [This question should only be answered by hospitals that are unable to provide an AMR value and other required information to E37.5 above.] **How many neonates and infants with congenital heart disease (CHD) had surgery prior to 1 year of age for their CHD in the following Society of Thoracic Surgery & European Association for Cardio-Thoracic Surgery Congenital Heart Surgery (STAT) Mortality Categories? Of those patients, how many experienced Operative Mortality during the episode of care associated with their first Index Cardiac Operation?** [Please calculate estimated gestational age (EGA) based on both weeks and days of EGA. If days are not available, then please use weeks only. Please count any given patient only one time. If a patient had more than one index cardiac operation, please assign the patient to the STAT Category associated with their first Index Cardiac Operation.If reporting based on the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024, a query of your individual institutional STS Congenital Heart Surgery Database can be made with these parameters or your hospital database can be used. [If none, please enter 0.]

For this question E37.6, please report these data for the four-year time period of July 1, 2020 through June 30, 2024. This includes operations based on their Primary Procedure using the STAT Mortality Score 2020, as described in the following manuscript: Jacobs ML, Jacobs JP, Thibault D, Hill KD, Anderson BR, Eghtesady P, Karamlou T, Kumar SR, Mayer JE, Mery CM, Nathan M, Overman DM, Pasquali SK, St Louis JD, Shahian D, O’Brien SM. Updating an Empirically Based Tool for Analyzing Congenital Heart Surgery Mortality. World J Pediatr Congenit Heart Surg. 2021 Mar;12(2):246-281. Doi: 10.1177/2150135121991528. PMID: 33683997.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Neonates (Less than or equal to 30 days old at the time of their index cardiac operation)** | **Unique Patients** | **Deaths** |
| a. | STAT Level 3 **(****HEART\_CHD2\_NEO\_LVL3\_** | **PAT)** | **DEATHS)** |
| b. | STAT Level 4 **(HEART\_CHD2\_NEO\_LVL4\_** | **PAT)** | **DEATHS)** |
| c. | STAT Level 5 **(HEART\_CHD2\_NEO\_LVL5\_** | **PAT)** | **DEATHS)** |

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Infants (31 days to 1 year old at the time of their index cardiac operation)** | **Unique Patients** | **Deaths** |
| d. | STAT Level 3 **(HEART\_CHD2\_INFANT\_LVL3\_** | **PAT)** | **DEATHS)** |
| e. | STAT Level 4 **(HEART\_CHD2\_INFANT\_LVL4\_** | **PAT)** | **DEATHS)** |
| f. | STAT Levels 5 **(HEART\_CHD2\_INFANT\_LVL5\_** | **PAT)** | **DEATHS)** |

NOTES: E37.6x1 and E37.6x2 should be whole number only. Do not allow decimals.

VALIDATE: IF E37.6x2>E37.6x1 DISPLAY: “Deaths cannot be greater than unique patients.”

1. **How many cardiac surgeries (see code list) were performed by a pediatric cardiac surgeon in your hospital during the 4 years from July 2020 through June 2024?** [If reporting STS data, use the “Operations in Analysis” row from Table 1 in the STS Congenital Heart Surgery Database Feedback report covering through June 30, 2024 for the same years. If not reporting STS data, use the code list provided.] [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Surgeries** |
| a. | Reporting year 1 (July 2020 – June 2021) **(HEART\_YR1\_ORPROCS)** | \_\_\_\_\_\_\_\_ |
| b. | Reporting year 2 (July 2021 – June 2022) **(HEART\_YR2\_ORPROCS)** | \_\_\_\_\_\_\_\_ |
| c. | Reporting year 3 (July 2022 – June 2023) **(HEART\_YR3\_ORPROCS)** | \_\_\_\_\_\_\_\_ |
| d. | Reporting year 4 (July 2023 – June 2024) **(HEART\_YR4\_ORPROCS)** | \_\_\_\_\_\_\_\_ |

NOTES: E38x should be whole number only. Do not allow decimals.

1. **Does your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program have at least two (2) current attending/on-staff congenital heart surgeons who have actively participated in 75 or more of the operations listed in question E38 as primary or first assistant (at any hospital or institution) during the year July 1, 2023 through June 30, 2024?[[42]](#footnote-43)**

**(HEART\_HEARTSURGEONS)**

* + Yes
  + No

1. **How many patients[[43]](#footnote-44) with hypoplastic left heart syndrome (HLHS)[[44]](#footnote-45) meeting the following criteria—single ventricle physiology as verified by a single ventricle management strategy through 1 year of age; inadequate systemic outflow tract requiring Norwood[[45]](#footnote-46) at Stage 1 or Stage 2; aortic arch obstruction requiring intervention, and for whom there was no formal plan for “comfort care”**[[46]](#footnote-47) **stated in the chart and there was a plan for intervention (surgery or catheterization) at either your institution or a transfer center—were managed at your institution as neonates in each of the following categories for each reporting year?**

(If reporting based on STS, refer to Table 28 for “Norwood Procedure” (first row of Table 28 provides Norwood incidence for HLHS for July 1, 2020- June 30, 2024). Hybrid Approach Stage 1, Stent placement in arterial duct (PDA) + application of RPA & LPA bands, Hybrid Approach Stage 1, Application of RPA & LPA bands, and Hybrid Approach Stage 1, Stent placement in arterial duct (PDA) + application of RPA & LPA internal flow restrictors must be obtained from hospital records). (Note that patients may only be counted once; if a patient undergoes more than one of these procedures, please count the patient only once using the first procedure.)[If none, please enter 0.]

Report the cumulative Norwood Stage 1 data for 4 years combined in row “a” of the table below. In the STS congenital Heart Surgery Database Feedback Report, this information can be found in the first row of Table 28. Data for all other requested values in rows “b”, “c”, “d”, and “e” of the table below should come from your hospital records.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | **Transferred to another center** | **Died prior to surgical intervention** | **Received Hybrid**  **(Stage 1)**  **as a planned bridge to transplant[[47]](#footnote-48)** |  | **Received Hybrid**  **(Stage 1)**  **NOT as a planned bridge to transplant** | **Received Norwood Stage 1** |
| a. | Reporting all 4 years combined  (July 2020–June 2024)  **(HEART\_SUM4YRS\_** |  | **TRANSFER)** | **DPI)** | **HYBPTX)** |  | **HYBRID)** | **NORWOOD)** |
| b. | Reporting year 1 (July 2020 – June 2021)  **(HEART\_YR1** |  | **TRANSFER)** | **DPI)** | **HYBPTX)** |  | **HYBRID)** | **NORWOOD)** |
| c. | Reporting year 2 (July 2021 – June 2022)  **(HEART\_YR2** |  | **TRANSFER)** | **DPI)** | **HYBPTX)** |  | **HYBRID)** | **NORWOOD)** |
| d. | Reporting year 3 (July 2022 – June 2023)  **(HEART\_YR3** |  | **TRANSFER)** | **DPI)** | **HYBPTX)** |  | **HYBRID)** | **NORWOOD)** |
| e. | Reporting year 4 (July 2023 – June 2024)  **(HEART\_YR4** |  | **TRANSFER)** | **DPI)** | **HYBPTX)** |  | **HYBRID)** | **NORWOOD)** |

NOTES: E40x1, E40x2, E40x3, E40x4, and E40x5 should be whole number only. Do not allow decimals.

VALIDATE: IF SUM (E40b1, E40c1, E40d1, E40e1) != E40a1, DISPLAY: “E40 (Transferred): The individual reporting years (rows b-e) should sum to the combined data (row a). Please review your inputs.”

IF SUM (E40b2, E40c2, E40d2, E40e2) != E40a2, DISPLAY: “E40 (Died prior to surgical intervention): The individual reporting years (rows b-e) should sum to the combined data (row a). Please review your inputs.”

IF SUM (E40b3, E40c3, E40d3, E40e3) != E40a3, DISPLAY: “E40 (Hybrid – planned bridge): The individual reporting years (rows b-e) should sum to the combined data (row a). Please review your inputs.”

IF SUM (E40b4, E40c4, E40d4, E40e4) != E40a4, DISPLAY: “E40 (Hybrid – not planned bridge): The individual reporting years (rows b-e) should sum to the combined data (row a). Please review your inputs.”

IF SUM (E40b5, E40c5, E40d5, E40e5) != E40a5, DISPLAY: “E40 (Norwood): The individual reporting years (rows b-e) should sum to the combined data (row a). Please review your inputs.”

SKIP LOGIC: IF SUM (E40a4, E40a5, E40b4, E40b5, E40c4, E40c5, E40d4, E40d5) > 0, GO TO E40.1; ELSE SKIP TO E42.

**E40.1 Of the patients you identified in E40 as receiving either a “Norwood (Stage 1) Operation” or a “Hybrid (Stage 1) Operation NOT as a planned bridge to transplant”, how many unique patients were alive without a heart transplant at 1 year of age?[[48]](#footnote-49)** [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Hybrid (Stage 1)**  **NOT as a planned bridge to transplant:**  **Patients Alive** | **Norwood (Stage 1):**  **Patients Alive** |
| a. | Unique patients alive, reporting year 1 (July 2020 – June 2021) **(HEART\_YR1\_ALIVE\_NT\_** | \_\_\_\_\_\_\_\_  **HYBRID)** | \_\_\_\_\_\_\_\_  **NORWOOD)** |
| b. | Unique patients alive, reporting year 2 (July 2021 – June 2022) **(HEART\_YR2\_ALIVE\_NT\_** | \_\_\_\_\_\_\_\_  **HYBRID)** | \_\_\_\_\_\_\_\_  **NORWOOD)** |
| c. | Unique patients alive, reporting year 3 (July 2022 – June 2023) **(HEART\_YR3\_ALIVE\_NT\_** | \_\_\_\_\_\_\_\_  **HYBRID)** | \_\_\_\_\_\_\_\_  **NORWOOD)** |

NOTES: E40.1x1 and E40.1x2 should be whole number only. Do not allow decimals.

For error messages below, E40.1 and E40 do not match one to one, please compare E40.1a to E40b, E40.1b to E40c, and E40.1c to E40d.

VALIDATE: IF E40.1x1 > E40x4, DISPLAY: “Number of Hybrid (NOT as a planned bridge to transplant) patients alive (E40.1x) cannot be greater the number of patients that received Hybrid surgery (E40x).”

IF E40.1x2 > E40x5, DISPLAY: “Number of Norwood patients alive (E40.1x) cannot be greater the number of patients that received Norwood surgery (E40x).”

**E40.2 Of the patients you identified in E40 as receiving either a Hybrid (Stage 1) or a Norwood (Stage 1) procedure, how many unique patients were alive (all patients including those with a heart transplant) at 1 year of age?[[49]](#footnote-50)** [If none, please enter 0.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Hybrid**  **(Stage 1)**  **as a planned bridge to transplant[[50]](#footnote-51):**  **Patients Alive** | **Hybrid**  **(Stage 1)**  **NOT as a planned bridge to transplant:**  **Patients Alive** | **Norwood (Stage 1):**  **Patients Alive** |
| a. | Unique patients alive, reporting year 1 (July 2020 – June 2021) **(HEART\_YR1\_ALIVE\_ALL** | \_\_\_\_\_\_\_\_  **HYBPTX)** | \_\_\_\_\_\_\_\_  **HYBRID)** | \_\_\_\_\_\_\_\_  **NORWOOD)** |
| b. | Unique patients alive, reporting year 2 (July 2021 – June 2022) **(HEART\_YR2\_ALIVE\_ALL** | \_\_\_\_\_\_\_\_  **HYBPTX)** | \_\_\_\_\_\_\_\_  **HYBRID)** | \_\_\_\_\_\_\_\_  **NORWOOD)** |
| c. | Unique patients alive, reporting year 3 (July 2022 – June 2023) **(HEART\_YR3\_ALIVE\_ALL** | \_\_\_\_\_\_\_\_  **HYBPTX)** | \_\_\_\_\_\_\_\_  **HYBRID)** | \_\_\_\_\_\_\_\_  **NORWOOD)** |

NOTES: E40.2x1, E40.2x2, and E40.2x3 should be whole number only. Do not allow decimals.

VALIDATE: IF E40.2x1 > E40x3, DISPLAY: “Number of Hybrid (planned as a bridge to transplant) patients alive (E40.2x) cannot be greater the number of patients that received Hybrid surgery (E40x).”

IF E40.2x2 > E40x4, DISPLAY: “Number of Hybrid (NOT as a planned bridge to transplant) patients alive (E40.2x) cannot be greater the number of patients that received Hybrid surgery (E40x).”

IF E40.2x3 > E40x5, DISPLAY: “Number of Norwood patients alive (E40.2x) cannot be greater the number of patients that received Norwood surgery (E40x).”

SKIP LOGIC: IF SUM (E40.1a1, E40.1a2, E40.1a3, E40.1b1, E40.1b2, E40.1b3, E40.1c1, E40.1c2, E40.1c3) > 0, GO TO E41; ELSE SKIP TO E42.

1. **Of the patients you identified in E40.1 who were alive at 1 year of age, how many were referred for and how many had a neurodevelopmental evaluation[[51]](#footnote-52) prior to 24 months of age?** [If none, please enter 0.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | |  | **Unique Patients Referred** | **Unique Patients Evaluated** |
| a. | Unique patients, reporting year 1 (July 2020 – June 2021) **(HEART\_YR1\_ALIVE\_NT\_NORWOOD\_** | | \_\_\_\_\_\_\_\_  **REF)** | \_\_\_\_\_\_\_\_  **EVAL)** |
| b. | Unique patients, reporting year 2 (July 2021 – June 2022) **(HEART\_YR2\_ALIVE\_NT\_NORWOOD \_** | | \_\_\_\_\_\_\_\_  **REF)** | \_\_\_\_\_\_\_\_  **EVAL)** |

NOTES: E41x1 and E41x2 should be whole number only. Do not allow decimals.

VALIDATE: IF E41x > (E40.1x1 +E40.1x2), DISPLAY: “Number of patients referred (E41x1) cannot be greater than the number of patients alive who received Hybrid Stage 1 or Norwood Stage 1 procedures (E40.1x).”

IF E41x2 > E41x1, DISPLAY: “E41x: Number of patients evaluated cannot be more than the number of patients referred.”

1. **How many unique patient admissions in the 4 reporting years from Question E38 received surgical procedures in the following Society of Thoracic Surgery & European Association for Cardio-Thoracic Surgery Congenital Heart Surgery (STAT) Mortality Categories? Of those patients, how many experienced Operative Mortality?** [If reporting based on STS, refer to Table 1 from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024 (Columns for each year June-July, 2020-2024: Rows: "Number of Mortalities" and "Number Eligible" for each STAT Category). For hospitals not participating in STS, count the volume and deaths according to the STAT definitions.[[52]](#footnote-53)] [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Reporting year 1** (July 2020 – June 2021) | **Unique Patients** | **Deaths** |
| a. | STAT Level 1  **(HEART\_YR1\_STAT1\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| b. | STAT Level 2  **(HEART\_YR1\_STAT2\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| c. | STAT Level 3  **(HEART\_YR1\_STAT3\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| d. | STAT Level 4  **(HEART\_YR1\_STAT4\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| e. | STAT Level 5  **(HEART\_YR1\_STAT5\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
|  | **Reporting year 2** (July 2021 – June 2022) | **Unique Patients** | **Deaths** |
| f. | STAT Level 1  **(HEART\_YR2\_STAT1\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| g. | STAT Level 2  **(HEART\_YR2\_STAT2\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| h. | STAT Level 3  **(HEART\_YR2\_STAT3\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| i. | STAT Level 4  **(HEART\_YR2\_STAT4\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| j. | STAT Levels 5  **(HEART\_YR2\_STAT5\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
|  | **Reporting year 3** (July 2022 – June 2023) | **Unique Patients** | **Deaths** |
| k. | STAT Level 1  **(HEART\_YR3\_STAT1\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| l. | STAT Level 2  **(HEART\_YR3\_STAT2\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| m. | STAT Level 3  **(HEART\_YR3\_STAT3\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| n. | STAT Level 4  **(HEART\_YR3\_STAT4\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| o. | STAT Levels 5  **(HEART\_YR3\_STAT5\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
|  | **Reporting year 4** (July 2023 – June 2024) | **Unique Patients** | **Deaths** |
| p. | STAT Level 1  **(HEART\_YR4\_STAT1\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| q. | STAT Level 2  **(HEART\_YR4\_STAT2\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| r. | STAT Level 3  **(HEART\_YR4\_STAT3\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| s. | STAT Level 4  **(HEART\_YR4\_STAT4\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |
| t. | STAT Levels 5  **(HEART\_YR4\_STAT5\_** | **\_\_\_\_\_\_\_\_**  **PATS)** | **\_\_\_\_\_\_\_\_**  **DEATHS)** |

NOTES: E42x1 and E42x2 should be whole number only. Do not allow decimals.

VALIDATE: IF E42x1 IS BLANK, DISPLAY: “E42x (Unique Patients): If none, please enter 0.”

If E42x2 > E42x1, DISPLAY: “E42x: Please check your responses. The number of patient deaths cannot be greater than the number of patients.”

IF E42x1 > 0 AND E42x2 IS BLANK, DISPLAY: “E42x (Deaths): If none, please enter 0.”

1. **What was the 4-year combined Risk-Adjusted Operative Mortality for your Pediatric and Congenital Cardiology and Cardiothoracic Surgery program?** [Please refer to Table 16 from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024. For the combined reporting years, as indicated in E18, please provide adjusted mortality rate (AMR) from the row “Neonates + Infants + Children + Adults, All STAT Mortality Categories.” Please leave this question blank if your program did not receive an adjusted mortality rate in Table 16.]

\_\_\_\_\_\_ a. 4-year combined adjusted mortality rate (AMR) **(HEART\_MORTRATIO4)**

\_\_\_\_\_\_ b. Lower limit of 4-year combined AMR confidence interval **(HEART\_MORTRATIO4\_LOW)**

\_\_\_\_\_\_ c. Upper limit of 4-year combined AMR confidence interval **(HEART\_MORTRATIO4\_UP)**

NOTES: E43x is numeric entry (decimals are allowed).

VALIDATE: If E43b > E43c, DISPLAY: “E43: Please check your responses. The upper limit of the confidence interval should be larger than the lower limit number of the confidence interval.”

If E43b > E43a, DISPLAY: “E43: Please check your responses. The AMR value should be larger than the lower limit number of the confidence interval.”

If E43a > E43c, DISPLAY: “E43: Please check your responses. The AMR value should be lower than the upper limit number of the confidence interval.”

If E43x is not numeric: “E43x: Please enter a numeric value.”

1. **What was the 4-year combined Risk-Adjusted Operative Mortality for your Pediatric and Congenital Cardiology and Cardiothoracic Surgery program in each of the following STAT Mortality Categories?** [Please refer to Table 16 from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024 for data from the time period of July 1, 2020 through June 30, 2024, inclusive. For the combined reporting years, as indicated in E18, please provide adjusted mortality rate (AMR) from the section titled “Neonates + Infants + Children + Adults” for each individual STAT Mortality Category. [Please leave this question blank if your program did not receive adjusted mortality rates in Table 16.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **STAT Level** | **4-year combined AMR** | **Lower limit of the AMR**  **confidence interval** | **Upper limit of the AMR**  **confidence interval** |
| a. | STAT Level 1 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT1** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| b. | STAT Level 2 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT2** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| c. | STAT Level 3 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT3** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| d. | STAT Level 4 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT4** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |
| e. | STAT Level 5 | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(HEART\_STAT5** | **\_AMR)** | **\_AMR\_LOWER)** | **\_AMR\_UPPER)** |

NOTES: E44x1, E44x2, and E44x3 is numeric entry (decimals are allowed).

VALIDATE: If E44x2 > E44x3, DISPLAY: “E44x: Please check your responses. The upper limit of the confidence interval should be larger than the lower limit number of the confidence interval.”

If E44x2 > E44x1, DISPLAY: “E44: Please check your responses. The AMR value should be larger than the lower limit number of the confidence interval.”

If E44x1 > E44x3, DISPLAY: “E44: Please check your responses. The AMR value should be lower than the upper limit number of the confidence interval.”

If E44x1, E44x2, or E44x3 is not numeric: “E44xX: Please enter a numeric value.”

1. **What were the median post-operative length of stay (PLOS) values for patients in each of the following STAT categories from your institution’s most recent STS report?** Please refer to Table 19 from the STS Congenital Heart Surgery Database Feedback Report covering through June 30, 2024.

|  |  |  |
| --- | --- | --- |
|  | **STAT Level** | **Median PLOS** |
| a. | STAT Level 1 **(HEART\_STAT1\_PLOS)** | \_\_\_\_\_\_\_\_ |
| b. | STAT Level 2 **(HEART\_STAT2\_PLOS)** | \_\_\_\_\_\_\_\_ |
| c. | STAT Level 3 **(HEART\_STAT3\_PLOS)** | \_\_\_\_\_\_\_\_ |
| d. | STAT Level 4 **(HEART\_STAT4\_PLOS)** | \_\_\_\_\_\_\_\_ |
| e. | STAT Level 5 **(HEART\_STAT5\_PLOS)** | **\_\_\_\_\_\_\_\_** |

NOTES: E45x is numeric entry (decimals are allowed).

If E45x is not numeric: “E45x: Please enter a numeric value.”

**E46. How many catheter ablations did your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program perform for accessory pathway with or without SVT from April 1, 2023 through March 31, 2024? Of those, how many were successful based on complete elimination of all accessory pathways at the end of the procedure?**

\_\_\_\_\_\_ a. Number of catheter ablations performed **(HEART\_ACCESSPATH)**

\_\_\_\_\_\_ b. Number of successful catheter ablations **(HEART\_ACCESSPATH\_SUCCESS)**

NOTES: E46x should be whole number only. Do not allow decimals.

**The following are being collected for information purposes only. They will not be factored into the rankings this year.**

**E47. Does your heart center have a dedicated[[53]](#footnote-54) mental health provider specifically for outpatient cardiac patients beyond pre-transplant evaluations?** [This mental health provider can be any of the following: (1) Psychiatrist and/or Child Psychiatrist (M.D. or D.O.), (2) Clinical Psychologist (PhD or PsyD), (3) Licensed Masters in Social Work (MSW), AND/OR (4) Licensed Mental Health Counselor (LMHC).]

**(HEART\_MENTAL\_PROVIDER)**

* Yes
* No

**E48. This question has been removed from the survey.**

**E49. This question has been removed from the survey.**

**E50. This question has been removed from the survey.**

**E51. This question has been remove from the survey.**

**CHIEF OF SERVICE APPROVAL**

To have this section of the survey accepted for scoring, the Service Chief for your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program must acknowledge that they have reviewed all responses and approve of the submission. To do this you will need to download, complete, and upload the approval form by the date of the final survey submission. Has the approval form for your Pediatric and Congenital Cardiology/Cardiothoracic Surgery program been completed and uploaded to the Pediatric Hospital Survey website?

**(HEART\_DIR\_APPROVE)**

* Yes, the form as been submitted
* No, the form has not been submitted. Please complete and upload the form before proceeding.

**COMMENTS FOR SECTION E:**

If needed, you may provide clarifications to the responses you provided to the questions asked in this section only. All other comments, suggestions or questions should be sent to [PediatricHospSurvey@rti.org](mailto:PediatricHospSurvey@rti.org).

|  |
| --- |
| **(HEART\_COMMENTS)** |

1. Attending/on-staff physicians include those who have completed their training in their particular medical specialty, are actively providing clinical care to patients, and are currently considered a member of the “medical staff” at the hospital. This may include physicians employed by the hospital, an affiliated university, or some other entity as long as the physician is considered part of the medical staff at the hospital. An individual with the academic title of "Instructor” who is on faculty and who has COMPLETED training would count; however, an individual with the academic title of "Instructor” who is in a Residency or Fellowship would NOT count. [↑](#footnote-ref-2)
2. A CICU is a specialized unit designed to meet the needs of pediatric cardiac patients, including (a) newborns diagnosed with critical congenital heart disease, (b) infants and children with congenital or acquired heart disease, (c) infants and children with arrhythmias, (d) candidates for heart transplantation, and (e) patients with heart disease who require intensive care services following noncardiac surgery. The CICU is staffed with a multidisciplinary care team, including cardiac intensivists, cardiothoracic surgeons, and dedicated cardiac nurses. “Dedicated” indicates the beds and staff are used exclusively for cardiothoracic patients except in rare overflow situations. [↑](#footnote-ref-3)
3. In-house attending coverage means that the listed providers are physically onsite and available at the hospital for night and weekend coverage throughout the shift. [↑](#footnote-ref-4)
4. Nights are defined as any time between 5pm and 5am the following morning. [↑](#footnote-ref-5)
5. Weekends are defined as any time between 5pm on Friday and 5am Monday morning. [↑](#footnote-ref-6)
6. Calculate nurse (RN) clinical FTEs based on total paid hours for the period of review divided by 2080. [↑](#footnote-ref-7)
7. To be eligible for CCRN certification, nurses must have >1,800 hours of critical care practice within the past 24 months. [↑](#footnote-ref-8)
8. https://intersocietal.org/programs/echocardiography/standards/ [↑](#footnote-ref-9)
9. These surgical operating rooms are designed and maintained for the surgical care of pediatric and adult congenital cardiac patients only. [↑](#footnote-ref-10)
10. A CICU is a specialized unit designed to meet the needs of pediatric cardiac patients, including (a) newborns diagnosed with critical congenital heart disease, (b) infants and children with congenital or acquired heart disease, (c) infants and children with arrhythmias, (d) candidates for heart transplantation, and (e) patients with heart disease who require intensive care services following noncardiac surgery. The CICU is staffed with a multidisciplinary care team, including cardiac intensivists, cardiothoracic surgeons, and dedicated cardiac nurses. “Dedicated” indicates the beds and staff are used exclusively for cardiac patients except in rare overflow situations. [↑](#footnote-ref-11)
11. This is an inpatient unit with specialized equipment allowing physicians, nurses, and other medical staff to monitor each patient’s status using real-time remote electronic monitoring equipment. [↑](#footnote-ref-12)
12. This program should be present in addition to ECMO and is designed to support the placement, monitoring, and support of patients who require the implantation of a ventricular assist device (VAD) to treat their heart condition. A VAD is a mechanical blood pump that supports the function of a ventricle. [↑](#footnote-ref-13)
13. To answer “Yes,” the clinic must have a designated pediatric cardiologist, a pediatric geneticist, a genetic counselor, and a nursing coordinator. [↑](#footnote-ref-14)
14. This question specifically addresses cases performed at your hospital based on your catheterization lab records. For this version of the questions, please use your catheterization lab records, EMR, or other records system rather than NCDR which is used for E11. This is unlike surgical cases in the STS Database, which may be related to all congenital cases a surgeon performs regardless of the hospital. [↑](#footnote-ref-15)
15. Please include all patients who received these catheterization procedures who are <18 years of age; for those >18 years of age, please only include if they have a diagnosis of congenital heart disease as noted in the code list. [↑](#footnote-ref-16)
16. Please include all patients who received these catheterization procedures who are <18 years of age; for those >18 years of age, please only include if they have a diagnosis of congenital heart disease as noted in the code list. [↑](#footnote-ref-17)
17. This is a multidisciplinary care program designed to address the needs of adults with congenital heart disease. Programs should include cardiothoracic surgeons, cardiac intensivists, cardiac interventionalists, and cardiac electrophysiologists. In addition, to address the needs of adult patients, the program should have access to specialists in high-risk pregnancy, genetics, fetal echocardiography, gastro-intestinal (GI) and liver disease, pulmonary, hematology, and psychology. [↑](#footnote-ref-18)
18. A formal transition program includes pre-transition, transition, and transfer components. The *pre-transition component* includes a practitioner who assess readiness for transition; introduces the concept of transition and transfer; and discusses topics including diet and exercise, high-risk behaviors, contraception and pregnancy, future educational and vocational goals, and lifelong care. The *transition component* includes the completion of a formal transition curriculum to prepare the patient for transition. The *transfer component* has a flexible timing of transfer and a coordinated transfer process between providers of pediatric cardiac care and adult cardiac care. [↑](#footnote-ref-19)
19. Report based on the years July 1, 2020 – June 30, 2024; if using the STS Congenital Heart Surgery Database Report, please submit Tables 1, 7, 16, 19, 21, 25, 27 and 28 from the report ending June 30, 2024 STS Congenital Heart Surgery Database Feedback Report. [↑](#footnote-ref-20)
20. To answer yes, the data for your program must appear on the STS website at: <http://www.sts.org/quality-research-patient-safety/sts-public-reporting-online> [↑](#footnote-ref-21)
21. Verification reports are available here: <https://www.srtr.org/transplant-centers/?query=&distance=50&location=&state=&recipientType=pediatric&organ=heart&sort=transplantRate>. If your reports do not match the values that are publicly available, please provide an explanation. [↑](#footnote-ref-22)
22. This may include adult patients (18 years or older) in recognition that many pediatric heart programs continue to treat patients with certain congenital conditions into adulthood. [↑](#footnote-ref-23)
23. This program tracks patients in their home environment, trains parents to assist in care, and establishes protocols for emergencies. [↑](#footnote-ref-24)
24. This program provides neurodevelopmental evaluation of children at risk for adverse neurological and developmental outcomes, including patients who underwent prior Hybrid (Stage 1) Operation or Norwood (Stage 1) Operation. These neurodevelopmental evaluations may be done by a cardiac-specific neurodevelopmental follow-up program or some other neurodevelopmental evaluation program available at your hospital (e.g., NICU based follow-up programs, developmental pediatrics or psychology-based follow-up programs, etc.), as long as this program routinely evaluates patients with congenital heart disease. Neurodevelopmental evaluation and follow-up performed by general pediatricians does not meet this definition of a Neurodevelopmental Follow Up Program and should be excluded. [↑](#footnote-ref-25)
25. A multi-disciplinary care program designed to address the needs of Fontan patients. Programs must include a designated pediatric and ACHD cardiothoracic surgeons, cardiologists, cardiac catheter interventionists, cardiac electrophysiologists, and hepatologists. In addition, to address the needs of the Fontan patient, the program should provide access to specialists with expertise in anticoagulation, neurodevelopmental evaluation and management, mental health, nutrition, bone health, contraception and pregnancy counseling, genetic counseling, and a social worker. [↑](#footnote-ref-26)
26. The clinic must have a designated pediatric cardiologist, maternal fetal medicine physician, fetal sonographer, advanced maternal testing (e.g., chorionic villus sampling), and genetic counselor [↑](#footnote-ref-27)
27. A multi-disciplinary care program to address the needs of patients with pulmonary hypertension. Programs must include at least one pediatric cardiologist with expertise in pulmonary hypertension and at least one pulmonologist with expertise in pulmonary hypertension, and programs must have access to cardiac interventionalists in their own program. Programs must be able to offer advanced therapeutics (e.g., IV Prostacyclin, IV Remodulin® (treprostinil)) and interventions. [↑](#footnote-ref-28)
28. A multi-disciplinary care program to address the needs of patients with neuromuscular diseases affecting the cardiac system (e.g., Duchenne muscular dystrophy, Becker muscular dystrophy, Friedrich’s ataxia, Limb Girdle muscular dystrophy, Myotonic dystrophy).  Programs must include pediatric cardiology with expertise in neuromuscular disorders, neurology, pulmonary, and OT/PT specialists. [↑](#footnote-ref-29)
29. Multidisciplinary care for patients with Marfan syndrome, Loeys-Dietz, Bicuspid Aortic Valve and other aortopathies. Programs must include a dedicated pediatric cardiologist with expertise in aortopathies, genetic counselor. [↑](#footnote-ref-30)
30. Multispecialty care for children and adolescents with hypertension, hyperlipidemia, obesity, and/or family history of early cardiovascular disease.  Programs should include a dedicated pediatric cardiologist, endocrinologist, and dietician [↑](#footnote-ref-31)
31. Dedicated clinic designed to monitor and follow-up patients with advanced heart failure and patients after cardiac transplantation. At the minimum, this program must include a dedicated pediatric cardiology director, a transplant coordinator, and nurse clinician. [↑](#footnote-ref-32)
32. To answer yes, single center or multicenter prospective studies must be listed at ClinicalTrials.gov. [↑](#footnote-ref-33)
33. To answer yes, single center or multicenter prospective studies must be listed at ClinicalTrials.gov. [↑](#footnote-ref-34)
34. Please use data from the "SIR-Pediatric Complex AR SSI Data by Procedure" report. Only use procedure codes defined as “CARD” by NHSN. [↑](#footnote-ref-35)
35. To answer yes, guidelines should be on a form (paper or electronic), approved for local use, posted in each patient’s chart to which they apply, and compliance with the Guidelines should be tracked in the form of a checklist or other mechanism. Hospitals may include another well-defined and tracked technique to reduce practice variation such as the Standardized Clinical Assessment and Management Plan or regular discussion and review of pathways by a multidisciplinary team. [↑](#footnote-ref-36)
36. Please count cases that are defined by STS complication codes:

    22: Unplanned cardiac reoperation during the postoperative or postprocedural time period, exclusive of reoperation for bleeding,

    24: Unplanned interventional cardiovascular catheterization procedure during the postoperative or postprocedural time period, or

    26: Unplanned non-cardiac reoperation during the postoperative or postprocedural time period. [↑](#footnote-ref-37)
37. Please count cases that are defined by STS complication code 240: Bleeding, Requiring reoperation. [↑](#footnote-ref-38)
38. Please count cases that are defined by STS complication codes:

    262: Wound infection – Deep wound infection, or

    270: Wound infection – Mediastinitis. [↑](#footnote-ref-39)
39. Please count cases that are defined by STS complication codes:

    74: Arrhythmia necessitating pacemaker, Permanent pacemaker, or

    75: Arrhythmia necessitating pacemaker, Temporary pacemaker. [↑](#footnote-ref-40)
40. Please use the INCIDENCE number for your site from “Table 25: AV Canal, Last 4 Years (Jul 2020 - Jun 2024)” for Complete AV Canal [↑](#footnote-ref-41)
41. Please use the Unplanned Cardiac Reoperation number for your site from “Table 25: AV Canal, Last 4 Years (Jul 2020 - Jun 2024)” for Complete AV Canal [↑](#footnote-ref-42)
42. May include cases from more than one institution and may average the cases from 2023 and 2024 if an institutional change occurred during 2024 for any of the attending/on-staff physicians. [↑](#footnote-ref-43)
43. Note that patients for whom “comfort care” is planned prior to any intervention, surgical or catheter based, should not be counted; to be removed from the count, the strategy of “comfort care” must be adopted within 72 hours from the time of admission at your center. [↑](#footnote-ref-44)
44. Please note that for the purposes of this survey, one should utilize the following definition of Hypoplastic Left Heart Syndrome (HLHS) that is provided by the 2021 International Paediatric and Congenital Cardiac Code (IPCCC) and the Eleventh Revision of the International Classification of Diseases (ICD-11) and utilized by The Society of Thoracic Surgeons Congenital Heart Surgery Database: Hypoplastic Left Heart Syndrome (HLHS) is defined as “A spectrum of congenital cardiovascular malformations with normally aligned great arteries without a common atrioventricular junction, characterized by underdevelopment of the left heart with significant hypoplasia of the left ventricle including atresia, stenosis, or hypoplasia of the aortic or mitral valve, or both valves, and hypoplasia of the ascending aorta and aortic arch.” (See: Jacobs, et al. Nomenclature for Pediatric and Congenital Cardiac Care: Unification of Clinical and Administrative Nomenclature - The 2021 International Paediatric and Congenital Cardiac Code (IPCCC) and the Eleventh Revision of the International Classification of Diseases (ICD-11). Cardiology in the Young. 2021 Jul;31(7):1057-1188. doi: 10.1017/S104795112100281X. PMID: 34323211) [↑](#footnote-ref-45)
45. Norwood is equivalent to Damus-Kaye-Stansel plus arch reconstruction. [↑](#footnote-ref-46)
46. Note that patients for whom “comfort care” is planned prior to any intervention, surgical or catheter based, should not be counted; to be removed from the count, the strategy of “comfort care” must be adopted within 72 hours from the time of admission at your center. [↑](#footnote-ref-47)
47. “Hybrid (Stage 1) Operation as a planned bridge to transplant” is defined as a Hybrid (Stage 1) Operation performed in a patient who has undergone a formal evaluation for cardiac transplantation prior to Hybrid ([Stage 1] Operation) with the resultant decision of this evaluation being to list the patient with UNOS for a new heart. [↑](#footnote-ref-48)
48. Note that vital status at one year cannot be assumed and must be verified by one of the following methods: 1) Your medical records document a visit/admission to your healthcare system at >= 1 year of age, or an outpatient visit to your healthcare system at > 9 months of age in a patient who has completed a total cavopulmonary anastomosis and was otherwise generally well at the time of the visit; 2) Your medical records document a visit/admission to a referring healthcare system at >= 1 year of age, or an outpatient visit a referring healthcare system at > 9 months of age in a patient who has completed a total cavopulmonary anastomosis and was otherwise generally well at the time of the visit; 3) Direct communication from a health worker at a referring institution in a written/electronic (letter, e-mail, text message) form documents #2 above; or 4) Direct communication with the family in a written/ electronic (letter, e-mail, text message) or verbal form documents the vital status at >= 1 year of age. [↑](#footnote-ref-49)
49. Note that vital status at one year cannot be assumed and must be verified by one of the following methods: 1) Your medical records document a visit/admission to your healthcare system at >= 1 year of age, or an outpatient visit to your healthcare system at > 9 months of age in a patient who has completed a total cavopulmonary anastomosis and was otherwise generally well at the time of the visit; 2) Your medical records document a visit/admission to a referring healthcare system at >= 1 year of age, or an outpatient visit a referring healthcare system at > 9 months of age in a patient who has completed a total cavopulmonary anastomosis and was otherwise generally well at the time of the visit; 3) Direct communication from a health worker at a referring institution in a written/electronic (letter, e-mail, text message) form documents #2 above; or 4) Direct communication with the family in a written/ electronic (letter, e-mail, text message) or verbal form documents the vital status at >= 1 year of age. [↑](#footnote-ref-50)
50. “Hybrid (Stage 1) Operation as a planned bridge to transplant” is defined as a Hybrid (Stage 1) Operation performed in a patient who has undergone a formal evaluation for cardiac transplantation prior to Hybrid ([Stage 1] Operation) with the resultant decision of this evaluation being to list the patient with UNOS for a new heart. [↑](#footnote-ref-51)
51. This is a neurodevelopmental evaluation of children following Hybrid Stage 1 or a Norwood Stage 1 surgery at risk for adverse neurological and developmental outcomes. The evaluation may be done by a cardiac-specific neurodevelopmental follow-up program or some other neurodevelopmental evaluation program available at your hospital (e.g., NICU based follow-up programs, developmental pediatrics or psychology based follow-up programs, etc.) as long as they routinely see patients with congenital heart disease. A patient seen by their general pediatrician for an evaluation does not meet this definition and should be excluded. [↑](#footnote-ref-52)
52. For information on classifying cardiac surgical procedures into STAT categories, see: Table 1 in *J Thoracic and Cardiovascular Surgery,* 2009; 138: 1139-1153 at <https://www.jtcvs.org/action/showPdf?pii=S0022-5223%2809%2901017-4>, or use the STAT Table included with this survey. [↑](#footnote-ref-53)
53. Dedicated is defined as the professional spends > 50% of their time working with pediatric and congenital cardiac patients and their families. [↑](#footnote-ref-54)