| Data Set Name | OUTLIBR100 | Observations | 920 |
|----------------------------|---------------------------------------|-----------------------------|------|
| Member Type | DATA | Variables | 73 |
| Engine | V9 | Indexes | 0 |
| Created | Tuesday, October 22, 2013 10:36:35 AM | Observation Length | 3872 |
| Last Modified | Tuesday, October 22, 2013 10:36:35 AM | Deleted Observations | 0 |
| Protection | | Compressed | NO |
| Data Set Type | | Sorted | NO |
| Label | | | |
| Data Representation | WINDOWS_64 | | |
| Encoding | wlatin1 Western (Windows) | | |

| Engine/Host Dependent Information | | | | | | |
|-----------------------------------|---|--|--|--|--|--|
| Data Set Page Size | 16384 | | | | | |
| Number of Data Set Pages | 231 | | | | | |
| First Data Page | 1 | | | | | |
| Max Obs per Page | 4 | | | | | |
| Obs in First Data Page | 1 | | | | | |
| Number of Data Set Repairs | 0 | | | | | |
| Filename | \\neri1\Projects\PHN\Protocols\SVR\Data Manuals\Public dataset_r100.sas7bdat | | | | | |
| Release Created | 9.0301M1 | | | | | |
| Host Created | X64_ES08R2 | | | | | |

| | Variables Ordered by Position | | | | | | |
|----|-------------------------------|------|-----|-----------|----------|---|--|
| # | Variable | Type | Len | Format | Informat | Label | |
| 1 | blind_id | Char | 12 | | | Blinded ID | |
| 2 | screen_age | Num | 8 | | | A3. <created var="">Age at date screening started, days</created> | |
| 3 | COMP_BY | Char | 3 | \$3. | \$3. | A4. Initials of person completing form | |
| 4 | DOB | Num | 8 | MMDDYY8. | | B1. Patient date of birth | |
| 5 | GENDER | Num | 8 | GENDER. | 3. | B2. Patient gender | |
| 6 | RACE | Num | 8 | RACE. | 3. | B3. Race | |
| 7 | RACEMR_S | Char | 50 | \$50. | \$50. | B3a. More than one race: specify | |
| 8 | RACEOT_S | Char | 50 | \$50. | \$50. | B3b. Other: specify | |
| 9 | HISPANIC | Num | 8 | YN. | 3. | B4. Is patient of Hispanic or Latino origin? | |
| 10 | BWT | Num | 8 | 5. | 5. | B5. Birth weight, g | |
| 11 | lowbwt | Num | 8 | | | <pre><created var=""> Birth weight <2500g, 1=Yes 2=No</created></pre> | |
| 12 | GESTAGE | Num | 8 | 3. | 3. | B6. Gestational age, weeks | |
| 13 | preterm | Num | 8 | | | <pre><created var="">Gestational age <37 weeks, 1=Yew 2=No</created></pre> | |
| 14 | bwtgrp | Num | 8 | NMED. | | <pre><created var=""> 1: BWT <=30th percentile for gestational age (GA) 2: BWT >30th and <=70th percentile for GA, 3: >70th percentile for GA</created></pre> | |
| 15 | PRENATDX | Num | 8 | YN. | 3. | C1. Prenatal diagnosis of congenital heart disease | |
| 16 | PNDXAGE | Num | 8 | 3. | 3. | C1a. Fetal age at prenatal diagnosis, weeks | |
| 17 | FETALINT | Num | 8 | YN. | 3. | C2. Fetal intervention | |
| 18 | AGEDXHR | Num | 8 | 3. | 3. | C3b. Age at diagnosis of congenital heart disease: Hours | |
| 19 | AGEDXDAY | Num | 8 | 3. | 3. | C3b. Age at diagnosis of congenital heart disease: Days | |
| 20 | adx | Char | 200 | \$LIST_O. | | C4. <created var="">Anatomic Diagnosis Code (Code List O)</created> | |
| 21 | ANATDX1 | Char | 2 | \$2. | \$2. | C4a. Level 1 | |
| 22 | ANATDX2 | Char | 2 | \$2. | \$2. | C4b. Level 2 | |
| 23 | ANATDX3 | Char | 2 | \$2. | \$2. | C4c. Level 3 | |
| 24 | ANATDX4 | Char | 2 | \$2. | \$2. | C4d. Level 4 | |
| 25 | ANDX_S | Char | 50 | \$50. | \$50. | C4a1. Level 1:specify | |
| 26 | ASSOCDX | Num | 8 | YN. | 3. | C5. Any associated anatomic diagnoses? | |
| 27 | asso_adx | Char | 200 | | | <created var=""> Concatenation of all associated anatomic diagnosis codes</created> | |
| 28 | ASDXCODE_0 | Char | 4 | \$LIST_I. | | C5a. Code associated anatomic diagnoses | |
| 29 | ASDXCODE_1 | Char | 4 | \$LIST_I. | | C5b. Code associated anatomic diagnoses | |
| 30 | ASDXCODE_2 | Char | 4 | \$LIST_I. | | C5c. Code associated anatomic diagnoses | |
| 31 | ASDXCODE_3 | Char | 4 | \$LIST_I. | | C5d. Code associated anatomic diagnoses | |
| 32 | ASDXCODE_4 | Char | 4 | \$LIST_I. | | C5e. Code associated anatomic diagnoses | |
| 33 | ASDX_S_0 | Char | 200 | \$20. | | C5a. 'Specify other' associated anatomic diagnoses | |

| | Variables Ordered by Position | | | | | | |
|----|-------------------------------|------|-----|--------|----------|---|--|
| # | Variable | Type | Len | Format | Informat | Label | |
| 34 | ASDX_S_1 | Char | 200 | \$20. | | C5b. 'Specify other' associated anatomic diagnoses | |
| 35 | ASDX_S_2 | Char | 200 | \$20. | | C5c. 'Specify other' associated anatomic diagnoses | |
| 36 | ASDX_S_3 | Char | 200 | \$20. | | C5d. 'Specify other' associated anatomic diagnoses | |
| 37 | ASDX_S_4 | Char | 200 | \$20. | | C5e. 'Specify other' associated anatomic diagnoses | |
| 38 | ATRESIA | Num | 8 | YN. | 3. | D1. Does patient have aortic atresia? | |
| 39 | OBSTRUCT | Num | 8 | YN. | 3. | D2. Does patient have obstructed pulmonary venous return? | |
| 40 | HLHS | Num | 8 | YN. | 3. | E1 <created var="">Hypoplastic left heart syndrome based on Anatomic Diagnosis Code</created> | |
| 41 | NORWPLAN | Num | 8 | YN. | 3. | E2. Is a Norwood procedure part of the treatment plan for this p | |
| 42 | LFVANOM | Num | 8 | YN. | 3. | E3. Single, morphologic left ventricle anomaly | |
| 43 | CONGENTL | Num | 8 | YN. | 3. | E4. Does patient have any major congenital abnormality | |
| 44 | HERNIA | Num | 8 | YN. | 3. | E4a. Congenital diaphragmatic hernia | |
| 45 | FISTULA | Num | 8 | YN. | 3. | E4b. Tracheoesophageal fistula | |
| 46 | NEEDVANT | Num | 8 | YN. | 3. | E4c. Need for high frequency ventilation | |
| 47 | RENAL | Num | 8 | YN. | 3. | E4d. Renal failure requiring dialysis | |
| 48 | TRISOM13 | Num | 8 | YN. | 3. | E4e. Trisomy 13 | |
| 49 | TRISOM18 | Num | 8 | YN. | 3. | E4f. Trisomy 18 | |
| 50 | CONGOTH | Num | 8 | YN. | 3. | E4g. Congenital: Other | |
| 51 | CONOTH_S | Char | 200 | \$200. | \$200. | E4g1. Congenital: Other: Specify | |
| 52 | NOSHUNT | Num | 8 | YN. | 3. | E5. Any preoperative anatomic evidence | |
| 53 | SUBCLAV | Num | 8 | YN. | 3. | E5a. Aberrant right subclavian artery | |
| 54 | CORONARY | Num | 8 | YN. | 3. | E5b. Significant conal coronary artery in proposed shunt area | |
| 55 | NOSHNOTH | Num | 8 | YN. | 3. | E5c. Evidence: Other | |
| 56 | NOSHNT_S | Char | 200 | \$200. | \$200. | E5d. Evidence: Other: specify | |
| 57 | DIED | Num | 8 | YN. | 3. | E6. Did patient die before screening could be completed? | |
| 58 | died_age | Num | 8 | | | E5a. <created var="">Age at date of death, days</created> | |
| 59 | OCENTFAR | Num | 8 | 3. | 3. | [Added version D]E7. Patient not approached to obtain Informed Consent? | |
| 60 | REASON_PT_NA | Num | 8 | 3. | 3. | [Added version D]E8a. Patient from outside of North America | |
| 61 | REASON_PT_LB | Num | 8 | 3. | 3. | [Added version D]E8b. Language barrier preventing informed consent | |
| 62 | REASON_PT_PO | Num | 8 | 3. | 3. | [Added version D]E8c. Outside referring physician objection | |
| 63 | REASON_PT_O | Num | 8 | 3. | 3. | [Added version D]E8d. Other | |
| 64 | REASON_PT_OS | Char | 500 | \$500. | \$500. | [Added version D]E8d1. Patient not approached: Other: specify | |
| 65 | comp_age | Num | 8 | | | F1. <created var="">Age at date completed screening, days</created> | |
| 66 | ELIGIBLE | Num | 8 | YN. | 3. | F2. Is patient eligible for trial? | |

| Variables Ordered by Position | | | | | | |
|-------------------------------|---------------|------|-----|-----------|----------|---|
| # | Variable | Type | Len | Format | Informat | Label |
| 67 | CONSENT | Num | 8 | YN. | 3. | G1. Did parent/guardian sign the informed consent document? |
| 68 | main549cohort | Num | 8 | YN. | | <pre><created var="">In the SVR main analysis cohort: 1=yes, 2=No</created></pre> |
| 69 | consent_age | Num | 8 | | | G1a. <created var="">Age at date consent signed</created> |
| 70 | NOCNST | Num | 8 | NOCNST_R. | 3. | G2. Reason for NOT signing Informed Consent Form: |
| 71 | NOCNST_S | Char | 500 | \$500. | \$500. | G2i. No consent: Other: specify |
| 72 | NOFAM | Num | 8 | NOFAM_R. | 3. | G2a. If family is unwilling to participate, specify reason: |
| 73 | NOFAM_S | Char | 500 | \$500. | \$500. | G2ai. Family unwilling: Other: specify |