

SAS Formats

The following data formats are used in the ISV data sets:

Acecode: 13 = Converting enzyme inhibitor

13.01 = Benazepril 13.02 = Captopril 13.03 = Cilarapril 13.04 = Enalaprilat 13.05 = Enalaprilat 13.06 = Fosinopril 13.07 = Lisinopril 13.08 = Pentropril 13.09 = Perindopril 13.1 = Quinapril 13.11 = Ramipril

13.12 = Tradolapril

13.99 = Other converting enzyme inhibitor

Air: 1 = Room air

2 = Oxygen

Ampm: 1 = AM

2 = PM 3 = 24-hour

Assessno: 1 = Significant delay

2 = Behavior

3 = Sensory impairment4 = Language barrier

Assoc: 1 = Not associated

2 = Possibly associated 3 = Probably associated

Botlprob: 1 = Bottle broken

2 = Bottle leaked 3 = No problem

Cineseq: 1 = Retrospective

2 = Prospective

Class: 1 = Class I

2 = Class II 3 = Class III 4 = Class IV

Confid: 1 = Very confident

2 = Somewhat confident 3 = Not at all confident

Consurg: 1 = Aortic arch repair

2 = Atrial septectomy

3 = Atrioventricular valve oversewn
4 = Atrioventricular valve replacement
6 = Division of main pulmonary artery
7 = Ligation of main pulmonary artery

8 = Pacemaker insertion

9 = Patch repair of pulmonary artery stenosis 10 = Repair of atrioventricular valve regurgitation

11 = Repair of totally anomalous pulmonary venous connection

14 = Semilunar valve replacement16 = Subaortic stenosis surgery99 = Other concurrent surgery

Coop: 1 = Fully cooperative

2 = Moderately cooperative

3 = Uncooperative

Determ: -8 = Indeterminate

1 = Determinate

Dfgrade: 0 = Normal

1 = Impaired relation2 = Pseudonormalization

3 = Restrictive

Echotype: 1 = Original

2 = Copy

Educ: 1 = Some high school or less

2 = High school graduate/GED 3 = Some college or 2-year degree

4 = 4-year college graduate

5 = Graduate degree

Ef: 1 = Normal (EF>55)

2 = Mild dysfunction (40<EF≤55) 3 = Moderate dysfunction (30<EF≤40) 4 = Severe dysfunction (EF≤30)

Feed: 1 = Tube feed group

2 = Bottle feed group3 = Breast feed group

Fs2amt: 1 =Never or rarely

2 = Some of the time 3 = Almost always

Fs2due: 1 = Fully

2 = Partly 3 = Not at all

G331type:	200 = AA
	210 = CC
	220 = GG

230 = TT 240 = DD 241 = II 300 = AC 301 = AG 311 = TC 340 = ID

Gender: 1 = Male

2 = Female

Hourwk: $1 = \langle 20 \text{ hours} \rangle$

2 = 21-39 hours3 = 40+ hours

Image: 1 = Excellent

2 = Good 3 = Fair

Income: -7 = Do not wish to provide

1 = < \$20,000

2 = \$20,000 - \$39,000 3 = \$40,000 - \$59,000 4 = \$60,000 - \$79,0005 = \$80,000 - \$99,000

6 = ≥\$100,000

Inoutpt: 1 = Inpatient

2 = Outpatient

Lang: 1 = English

2 = Spanish

Missed_r: 1 = Appointment problem

2 = Parent/guardian declined procedure

3 = Unable to complete procedure

4 = Self-administered form not returned

5 = Patient death

99 = Other

Mri_loc: 1 = 2-chamber

2 = 4-chamber 3 = Short axis

4 = Ascending aorta 5 = AV valve(s)

6 = SVC

7 = IVC/Right atrium junction

8 = IVC-SVC pathway (tunnel or conduit)

9 = Right pulmonary artery10 = Left pulmonary artery11 = Main pulmonary artery

12 = Coronal stack 13 = Axial stack 14 = Sagittal stack

99 = Other

Mri seq: -8 = Indeterminate

1 = Non-gated fast (turbo) gradient echo2 = ECG-gated fast (turbo) gradient echo3 = ECG-gated steady state free procession

4 = Standard spin echo 5 = Fast (turbo) spin echo

6 = Phase contrast

7 = Fast (turbo) phase contrast 8 = Contrast-enhanced MRA

99 = Other

Nobnp: 1 = Insufficient quantity

2 = Hemolysis 99 = Other

Nocnst_r: 1 = Open label use of ACE inhibitor is planned

2 = Family unwilling to participate in research study

3 = Language barrier

99 = Other

Nofam_r: 1 = Because of time commitment

2 = Because of distance from center

3 = No reason given

99 = Other

Noglen: 1 = Listed for transplant

99 = Other

Obtained: 1 = Obtained

2 = Not obtained

Othsurg: 1 = Chest closure

2 = Chest exploration without intervention

3 = Diaphragm plication 4 = Pacemaker insertion

5 = Percutaneous enteral gastrostomy

7 = Pleurodesis

8 = Pulmonary artery band revision

9 = Pulmonary artery plasty

10 = Shunt revision or thrombectomy

11 = Thorocentesis

12 = Thoracic duct ligation13 = Thoracostomy tube

99 = Other cardiac surgical procedure

Phase: 1 = Uptitration

2 = Maintenance

Propofol: 1 = Propofol

99 = Other

Race: 1 = White

2 = Black or African American

3 = Asian

4 = American Indian or Alaskan Native

5 = Native Hawaiian or other Pacific Islander

6 = More than one race

7 = Other99 = Other

Record_a: -1 = Structure not present

1 = Recorded 2 = Not recorded 3 = Inadequate

Record b: 1 = Recorded

2 = Not recorded

3 = Technically inadequate

Related: 1 = Not related

2 = Possibly related 3 = Probably related

Relation: 1 = Biological parent

2 = Step parent 3 = Foster parent 4 = Adoptive parent

5 = Guardian 99 = Other

Restrict: 1 = Present

2 = Absent

Rhythm: 1 = Sinus2 = Paced

99 = Other

S300sed: 1 = General anesthesia

2 = Moderate sedation

3 = No sedation

Scanner: 1 = General electric

2 = Siemens 3 = Phillips 99 = Other

Sedation: 1 = General anesthesia

2 = Conscious sedation

3 = No sedation

Serious: 1 = Not serious

2 = Moderately serious

3 = Serious 4 = Death

Severe2_: 1 = None/mild

2 = Moderate/severe

Severe3_: -8 = Indeterminate

1 = Mild 2 = Moderate 3 = Severe

Severe4_: -8 = Indeterminate

1 = None 2 = Mild 3 = Moderate 4 = Severe

State: 1 = Calm

2 = Agitated

Stoprs: 1 = Glenn shunt surgery

2 = Hypotension 3 = Hypoxia 4 = Vomiting 5 = Acute illness 6 = NPO status 7 = Repail dysfunc

7 = Renal dysfunction

99 = Other

Svadxcat: 1 = DILV2 = DIRV3 = SV:MA4 = SV:TA5 = SV:Unbalanced AVC R dominant 6 = SV:Unbalanced AVC L dominant 7 = PA/IVS8 = HLHS9 = Other SV10 = Two ventricles Testtype: 1 = Echocardiogram 2 = Cardiac MRI 3 = Neurodevelopmental 4 = Venipuncture Visit: 0 = Baseline1 = Study visit 1 (Day 4) 2 = Study visit 2 (Week 2) 3 = Study visit 3 (Pre-Glenn) 4 = Study visit 4 (Restart) 5 = Study visit 5 (Age 10 month) 6 = Study visit 6 (Age 14 month) Wdrw r: 1 = Family withdrew patient 2 = Physician withdrew patient 3 = Patient lost to follow-up 4 = Patient death 5 = Open-label use of ACE inhibitor 6 = Heart transplant 99 = OtherYn: -8 = Unknown-1 = NA1 = Yes2 = NoYnas: 1 = Yes2 = No3 = Not assessed Ynst: -8 = Indeterminate -1 = Structure not present 1 = Yes2 = No

Ampmc:

1 = AM 2 = PM 3 = 24-hour

List_a: See code list A

List_b: See code list B

List_d: See code list C

List_f: See code list F

List_i: See code list I