Supplemental Table 1. Mutually exclusive congenital heart defect severity categories by International Classification of Disease version 9.0 Clinical Modification codes

|  |  |  |
| --- | --- | --- |
| **Category** | **ICD-9-CM\* Code** | **Code Description** |
| **SEVERE**  *(if case has a severe code, regardless of presence of shunt, valve, or other codes)* | 745.0  745.1  745.10  745.11  745.12  745.19  745.2  745.3  745.6  745.60  745.69  746.01  746.1  746.7  747.11  747.41 | Common truncus  Transposition of the great arteries (TGA)  Complete TGA (dextro-TGA), not otherwise specified (NOS) or classical  Double outlet right ventricle, or incomplete TGA  Corrected TGA (levo-TGA)  TGA Other  Tetralogy of Fallot  Single ventricle, or cor triloculare  Endocardial cushion defect  Endocardial cushion defect unspecified  Endocardial cushion defect, other  Pulmonary valve atresia or absence  Tricuspid atresia, stenosis or absence  Hypoplastic left heart syndrome  Interrupted aortic arch  Total anomalous pulmonary venous return |
| **SHUNT + VALVE**  *(case has shunt AND valve codes)* | A combination of the shunt/valve codes below | A combination of the shunt/valve defects below |
| **SHUNT**  *(case has at least one shunt code, no valve or severe codes)* | 745.4  745.5  745.61  745.8  745.9  747.0  747.42 | Ventricular septal defect (VSD)  Atrial septal defect (ASD secundum or Patent Foramen Ovale  ASD primum  Other specified defect of septal closure  Unspecified defect of septal closure  Patent ductus arteriosus (PDA)  Partial anomalous venous return |
| **VALVE**  *(case has at least one valve code, no shunt or severe codes)* | 746.0  746.00  746.02  746.09  746.2  746.3  746.4†  746.5  746.6†  764.81  746.83  747.1 / 747.10  747.22  747.3†  747.31  747.39 | Anomalies of pulmonary valve  Pulmonary valve anomaly, unspecified  Pulmonary valve stenosis  Pulmonary valve anomaly, other  Ebstein Anomaly  Aortic valve stenosis  Aortic insufficiency or bicuspid/unicuspid aortic valve†  Mitral stenosis or mitral valve abnormalities  Mitral insufficiency†  Subaortic stenosis  Infundibular or subvalvar pulmonary stenosis  Coarctation of aorta  Atresia or stenosis of aorta  Anomalies of pulmonary artery†  Pulmonary artery atresia, coarctation, or hypoplasia  Anomalies of pulmonary artery, other |
| **OTHER ONLY**  *(case only has one or more codes in this category)* | 745.7  746.8  746.82  746.84  746.85  746.87  746.89†  746.9†  747.2  747.20  747.21  747.29  747.4  747.40  747.49  747.9  648.5x  V13.5 | Cor biloculare  Other specified anomalies of heart  Cor triatriatum  Obstructive anomalies of heart  Coronary artery anomaly  Malposition of heart or apex  Other specified anomaly of heart (various types) †  Unspecified defect of heart†  Other anomalies of the aorta  Anomalies of aorta, unspecified  Anomaly of aortic arch  Other anomalies of aorta, other specified  Anomalies of great veins  Anomalies of great veins, unspecified  Other anomalies of great veins  Unspecified anomalies of circulatory system  Congenital cardiovascular disorders in the mother  Personal history of (corrected) congenital malformations of heart and circulatory system |

\*International Classification of Disease version 9.0 Clinical Modification

†Codes considered to be minor. All other listed codes considered to be major.

Supplemental Table 2. Population-based denominator data, total and by age group, 5 sites\*, 2011-2013

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Age 1-10** | | | **Age 11-18** | | | **Age 19-44** | | | **Age 45-64** | | | **Age 11-64** | | |
|  | Total | Male | Female | Total | Male | Female | Total | Male | Female | Total | Male | Female | Total | Male | Female |
| **Colorado** | N/A | N/A | N/A | 546,340 | 280,377 | 265,963 | 1,907,201 | 981,510 | 925,691 | 1,368,673 | 676,867 | 691,806 | 3,822,214 | 1,938,754 | 1,883,460 |
| **5-county metropolitan-Atlanta, GA** | 495,505 | 252,114 | 243,391 | 389,206 | 198,346 | 190,860 | 1,359,418 | 664,503 | 694,915 | 876,967 | 415,913 | 461,054 | 2,625,591 | 1,278,762 | 1,346,829 |
| **11-County New York** | 583,279 | 297,392 | 285,887 | 511,323 | 261,680 | 249,643 | 1,599,360 | 785,438 | 813,922 | 1,247,485 | 593,463 | 654,022 | 3,358,168 | 1,640,581 | 1,717,587 |
| **North Carolina** | 1,265,527 | 645,956 | 619,571 | 1,029,535 | 526,044 | 503,491 | 3,419,352 | 1,702,917 | 1,716,435 | 2,573,855 | 1,236,954 | 1,336,901 | 7,022,742 | 3,465,915 | 3,556,827 |
| **Utah** | N/A | N/A | N/A | 366,895 | 188,726 | 178,169 | 1,086,820 | 551,714 | 535,106 | 566,864 | 281,451 | 285,413 | 2,020,579 | 1,021,891 | 998,688 |
| **Total** | 2,344,311 | 1,195,462 | 1,148,849 | 2,843,299 | 1,455,173 | 1,388,126 | 9,372,151 | 4,686,082 | 4,686,069 | 6,633,844 | 3,204,648 | 3,429,196 | 18,849,294 | 9,345,903 | 9,503,391 |

\* The denominator for overall, age-specific, and sex-specific populations at each site was estimated by averaging 2011, 2012, and 2013 U.S. Census estimates

Supplemental Table 3. Case contribution of 1 to 64-year-olds with a CHD-related ICD-9-CM code\* by data source type†, overall and by surveillance site, 2011-2013

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **CO** | **5-county metropolitan-Atlanta, GA** | **11-county NY** | **NC** | **UT** | **Total** |
|  | N (%) | N (%) | N (%) | N (%) | N (%) | N (%) |
| **Data source type** |  |  |  |  |  |  |
| All Payer Claims Database | 3,695 (56.8) | 0 | 0 | 0 | 0 | 3,695 (8.7) |
| Clinical Database | 4,788 (73.5) | 6,032 (72.6) | 4,397 (40.7) | 12,618 (100) | 4,370 (99.2) | 32,205 (75.5) |
| Hospital Discharge | 0 | 0 | 9,529 (88.2) | 0 | 2,231 (50.7) | 11,760 (27.6) |
| Medicaid | 0 | 2,987 (35.9) | 6,885 (63.7) | 0 | 0 | 9,872 (23.1) |
| Surgical Database | 0 | 437 (5.3) | 0 | 0 | 0 | 437 (1) |

\*Excluding isolated 745.5, 745.5 co-occurring with a non-specific CHD code, or ≥ 1 non-specific CHD code

†Individuals may appear in one or more data source

Supplemental Figure 1. Percentage by age group of 1 to 64-year-olds with a non-severe CHD-related ICD-9-CM code\* per 1,000 individuals, total and sex-specific, 5 sites†, 2011-2013

\*Excluding isolated 745.5, 745.5 co-occurring with a non-specific CHD code, or ≥ 1 non-specific CHD code

†Estimatefor 1 to 10-year-olds based on 3 sites: 5-county metropolitan-Atlanta, GA, 11 counties in NY state, statewide in NC; 11-18, 19-44, and 45-64-year-old estimates based on 5 sites: statewide in CO, 5-county metropolitan-Atlanta, GA, 11 counties in NY state, statewide in NC, and statewide in UT.

Central Illustration. Percentage by age group of 1 to 64-year-olds with a CHD-related ICD-9-CM code\* per 1,000 individuals, total and by CHD severity†, 5 sites‡, 2011-2013

\*Excluding isolated 745.5, 745.5 co-occurring with a non-specific CHD code, or ≥ 1 non-specific CHD code

†Non-severe = shunt + valve, valve, and shunt categories combined

‡Estimatefor 1 to 10-year-olds based on 3 sites: 5-county metropolitan-Atlanta, GA, 11 counties in NY state, statewide in NC; 11-18, 19-44, and 45-64-year-old estimates based on 5 sites: statewide in CO, 5-county metropolitan-Atlanta, GA, 11 counties in NY state, statewide in NC, and statewide in UT.