

SUPPLEMENTAL MATERIAL

Supplemental Table 1. Congenital heart defect (CHD)-related Centers for Disease Control and Prevention (CDC)-modified version of the British Pediatric Association (BPA) codes included and excluded from the Congenital Heart Survey To Recognize Outcomes, Needs, and well-being (CH STRONG) by CHD severity

Severe Codes	
745.000	Common Truncus
745.010	Aortic septal defect / Aortopulmonary window
745.100—	
745.190	Transposition (all types)
	745.100 Transposition of great vessels, complete (no VSD)
	Transposition of great vessels, incomplete (w/ VSD), Taussig
	745.110 Bing
	745.120 Corrected transposition of great vessels, L transposition, vent inversion
	745.190 Unspecified transposition of great vessels
745.200	Tetralogy of Fallot
745.210	Fallot's pentalogy (tetralogy plus ASD)
745.300	Single ventricle, common ventricle, cor triloculare biatriatum
745.620	Common atrioventricular canal with ventricular septal defect (VSD)
745.630	Common atrioventricular canal
745.680	Other specified cushion defect

745.690	Endocardial cushion defect, NOS
746.000	Pulmonary valve atresia, hypoplasia
746.100	Tricuspid atresia and stenosis
746.505	Absence, atresia, or hypoplasia of mitral valve
746.700	Hypoplastic Left Heart Syndrome (HLHS)
747.100—	
747.190	Coarctation of the aorta (all types)
	747.100 Pre-ductal
	747.110 Post-ductal
	747.120 Ductal
747.200	Aortic atresia (including pseudotruncus arteriosus)
747.210	Aortic hypoplasia
747.215—	
747.217, or 747.285	Interrupted aortic arch
747.420	Total Anomalous Pulmonary Venus Return (TAPVR)

Shunt + Valve Codes

745.520	Lutembacher syndrome
746.840	Trilogy of Fallot
<i>Other cases will be in this category if have codes in both Shunt and Valve categories.</i>	

Shunt Codes

745.400—745.490	Ventricular Septal Defect (VSD), (all types)
745.400	Roger's disease
745.410	Eisenmenger's syndrome
745.420	Gerbode defect
745.480	Other specified ventricular septal defect
745.490	Ventricular septal defect, NOS
745.510	Secundum atrial septal defect
745.580	Other specified atrial septal defect
745.590	Atrial septal defect, NOS
745.600	Ostium primum defects
745.610	Single common atrium, cor triloculare biventriculare
745.800	Other bulbus cordis anomalies and anomalies of cardiac septal closure
745.900	Unspecified defect of septal closure
747.430	Partial anomalous pulmonary venous return (PAPVR)

Valve Codes

746.010	Pulmonary valve stenosis
746.830	Pulmonary infundibular stenosis
746.080	Other specified anomalies of the pulmonary valve
746.090	Unspecified anomaly of pulmonary valve
746.200	Ebstein anomaly

746.300	Aortic valve stenosis (includes valvar and subvalvar)
747.220	Supra-aortic stenosis (supra-valvar)
746.480	Other specified anomalies of aortic valve (including aortic valve atresia)
746.790	Unspecified anomalies of aortic valve
746.500	Congenital mitral stenosis
746.900	Unspecified anomalies of heart valves
746.995	Pulmonic or pulmonary atresia, stenosis, or hypoplasia, NOS
747.300	Pulmonary artery atresia, absence, or agenesis
747.310	Pulmonary artery atresia with septal defect

Other Codes	
745.700	Cor biloculare
746.820	Cor triatriatum
746.881	Hypoplastic left ventricle
746.882	Hypoplastic right heart/ ventricle (Uhl's disease)
746.883	Hypoplastic ventricle, NOS
746.885	Coronary artery anomaly
746.887	Other defects of the atria
746.910	Anomalous bands of heart
746.920	Acyanotic congenital heart disease, NOS
746.930	Cyanotic congenital heart disease, NOS
747.230—747.290	Anomalies of aorta (all types)

747.230	Persistent right aortic arch
747.240	Aneurysm of sinus of Valsalva
747.250	Vascular ring (includes double aortic arch)
747.260	Overriding aorta
747.270	Aortic aneurysm
747.280	Other specified anomalies of aorta
747.290	Unspecified anomalies of aorta
747.400	Stenosis of vena cava (inferior or superior)
747.410	Persistent left superior vena cava

NOS: Not otherwise specified

EXCLUSIONS: Case excluded if ONLY has one or more of these codes:

745.xx8, 746.xx8, 747.xx8 ANY CHD code which is considered “possible or probable” by using an “8” as the 6th digit.

- 745.500 Patent foramen ovale
- 746.020 Pulmonary insufficiency
- 746.105 Tricuspid valve insufficiency
- 746.400 Aortic insufficiency/Bicuspid aortic valve
- 746.600 Mitral insufficiency
- 746.800 Dextrocardia
- 746.810 Levocardia
- 746.850 Anomalies of pericardium
- 746.860 Anomalies of myocardium
- 746.870 Congenital heart block
- 746.880 Other specified anomaly of heart
- 746.886 Ventricular hypertrophy
- 746.990 Unspecified anomalies of heart

- 747.000 Patent ductus arteriosus
- 747.320 Pulmonary artery stenosis
- 747.325 Peripheral pulmonary artery stenosis
- 747.330 Aneurysm of pulmonary artery
- 747.340 Pulmonary arteriovenous malformations

- 747.380 Other specified anomaly of pulmonary artery
- 747.390 Unspecified anomaly of pulmonary artery
- 747.440 Anomalous portal vein termination
- 747.450 Portal-hepatic vein fistula
- 747.480 Other specified anomalies of great veins
- 747.490 Unspecified anomalies of great veins
- 747.500 Single umbilical artery

- 747.6xx Other anomalies of peripheral vascular system, including:
 - 747.600 Stenosis of renal artery
 - 747.610 Other anomalies of renal artery
 - 747.620 Arteriovenous malformation (peripheral)
 - 747.630 Congenital phlebectasia, congenital varix
 - 747.640 Other anomalies of peripheral arteries, including aberrant subclavian artery
 - 747.650 Other anomalies of peripheral veins
 - 747.680 Other anomalies of peripheral vascular system
 - 747.690 Unspecified anomalies of peripheral vascular system

- 747.8xx Other specified anomalies of circulatory system, including:
 - 747.800 Arteriovenous (malformation) aneurysm of brain
 - 747.810 Other anomalies of cerebral vessels
 - 747.880 NOS anomalies of circulatory system

- 747.9xx Unspecified anomaly of circulatory system

Supplemental Table 2. Kaplan-Meier Survival Tables, CH STRONG

A. Overall

Age in years	% Survival (95% CI)
0	87.6 (87.0-88.2)
1	85.0 (84.3-85.6)
10	83.7 (83.0-84.4)
20	82.8 (82.1-83.5)
30	81.5 (80.7-82.2)
35	81.4 (80.6-82.2)

B. By CHD severity

Age in years	% Survival (95% CI)				
	Severe	Shunt+Valve	Shunt	Valve	Other
0	75.6 (74.3-76.9)	94.1 (92.6-95.6)	94.8 (94.1-95.4)	93.7 (92.4-95.1)	90.6 (87.6-93.6)
1	71.1 (69.7-72.5)	92.5 (90.8-94.2)	93.2 (92.5-94.0)	91.8 (90.4-93.4)	87.8 (84.5-91.2)

10	68.8 (67.4-70.3)	91.6 (89.9-93.4)	92.5 (91.8-93.3)	91.1 (89.5-92.6)	86.7 (83.2-90.3)
20	67.5 (66.1-69.0)	91.1 (89.3-93.0)	91.8 (91.1-92.6)	90.2 (88.6-91.9)	86.1 (82.6-89.8)
30	66.3 (64.8-67.9)	89.0 (86.7-91.4)	90.8 (89.9-91.7)	88.3 (86.2-90.4)	85.6 (81.9-89.3)
35	66.3 (64.8-67.9)	87.5 (83.9-91.3)	90.8 (89.9-91.7)	88.3 (86.2-90.4)	85.6 (81.9-89.3)

C. By primary diagnosis

% Survival (95% CI)

Age in years	AV Canal	HLHS	SV	TA-PS	TA+PS	TGA	TOF	Oth/Mult
0	85.6 (82.4-88.9)	26.9 (22.7-31.8)	70.1 (62.6-78.5)	78.7 (72.4-85.5)	87.2 (77.3-98.3)	73.9 (70.5-77.6)	83.6 (80.9-86.5)	91.2 (90.6-91.8)
1	79.6 (76.0-83.4)	24.2 (20.2-29.0)	63.0 (55.1-72.0)	74.7 (68.0-82.0)	82.1 (70.8-95.0)	72.1 (68.6-75.8)	82 (79.1-85.0)	89.1 (88.5-89.8)
10	77.8 (74.1-81.8)	22.6 (18.7-27.3)	55.1 (47.1-64.5)	69.3 (62.3-77.1)	79.5 (67.8-93.2)	71.1 (67.5-74.8)	80.9 (78.0-84.0)	88.1 (87.4-88.7)
20	75.5 (71.6-79.6)	21.5 (17.7-26.1)	53.5 (45.5-63.0)	66.0 (58.8-74.0)	76.9 (64.8-91.4)	69.8 (66.1-73.7)	80.4 (77.4-83.5)	87.3 (86.6-88.0)
30	73.3 (68.9-78.1)	21.5 (17.7-26.1)	53.5 (45.5-63.0)	61.3 (52.2-72.0)	NA	69.8 (66.1-73.7)	80.4 (77.4-83.5)	86.1 (85.3-86.9)
35	73.3 (68.9-78.1)	21.5 (17.7-26.1)	53.5 (45.5-63.0)	61.3 (52.2-72.0)	NA	NA	NA	85.9 (85.1-86.8)

AV = Atrioventricular, CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG, CHD = Congenital Heart Defect,

CI = Confidence Interval, HLHS = Hypoplastic Left Heart Syndrome, NA = , Oth/Mult= Other/Multiple, SV=Single Ventricle, TA-PS=Tricuspid

Atresia without Pulmonary Stenosis, TA + PS = Tricuspid Atresia with Pulmonary Stenosis, TGA= Transposition of the Great Arteries, TOF =

Tetralogy of Fallot

Supplemental Table 3. Adjusted risk ratios for death during the first year of life for individuals with CHD born between 1980 and 1997, CH STRONG – complete case analyses

Characteristic	Any CHD (n=11,338)		Severe CHD (n=4,035)		Non-Severe CHD (n=7,303)	
	aRR	95% CI	aRR	95% CI	aRR	95% CI
CHD severity*						
Severe	4.78	4.00, 5.75				
Shunt+Valve	1.29	0.89, 1.82				
Shunt	—	—				
Valve	1.24	0.88, 1.72				
Other	2.03	1.32, 3.01				
Has non-cardiac congenital anomalies†						
Syndromes	2.33	1.94, 2.79	1.07	0.85, 1.35	6.46	4.64, 8.97
Other	1.71	1.47, 1.99	1.20	0.99, 1.44	3.31	2.47, 4.45
None	—	—	—	—	—	—
Year of birth‡						
1980-1985	1.54	1.31, 1.80	1.02	0.84, 1.23	1.84	1.36, 2.45
1986-1990	1.19	1.06, 1.34	1.07	0.93, 1.22	1.27	1.02, 1.57
1991-1997	—	—	—	—	—	—
Sex§						

Male	—	—	—	—	—	—
Female	0.92	0.83, 1.03	1.08	0.95, 1.22	0.91	0.75, 1.10
Birth weight^{//}						
Low (<2500 grams)	1.76	1.51, 2.03	1.65	1.36, 2.00	3.18	2.45, 4.14
Normal (≥2500 grams)	—	—	—	—	—	—
Plurality[#]						
Single	—	—	—	—	—	—
Multiple	0.94	0.66, 1.29	1.09	0.7, 1.62	1.04	0.58, 1.71
Maternal						
race/ethnicity^{**}						
NH White	—	—	—	—	—	—
NH Black	1.27	1.10, 1.47	1.25	1.05, 1.50	1.46	1.12, 1.88
Hispanic	0.96	0.60, 1.45	1.10	0.62, 1.83	0.82	0.36, 1.65
NH Other	1.42	0.88, 2.17	1.57	0.92, 2.5	0.76	0.23, 1.86
County deprivation						
tertile^{††}						
T1 - Least deprivation)	—	—	—	—	—	—
T2	1.03	0.84, 1.26	0.91	0.71, 1.16	1.34	0.94, 1.90
T3 - Most deprivation	1.06	0.89, 1.28	0.99	0.79, 1.24	1.16	0.84, 1.61
Rural tertile^{‡‡}						
T1 - Least rural	—	—	—	—	—	—

T2	0.93	0.74, 1.15	1.09	0.83, 1.41	0.82	0.55, 1.22
T3 - Most rural	0.87	0.65, 1.17	1.08	0.76, 1.54	0.67	0.39, 1.13

aRR = adjusted Risk Ratio, CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs and well-being, CHD = Congenital Heart Defect, CI = Confidence Interval, NH = Non-Hispanic, T = Tertile; — indicates reference group

*Model includes CHD severity, non-cardiac congenital anomalies, birth year, site, sex, maternal race/ethnicity, and county deprivation tertile at birth

†Model includes non-cardiac congenital anomalies, birth year, site, sex, plurality, maternal race/ethnicity, and county deprivation tertile at birth

‡Model includes birth year and site

§Model includes sex and birth year

||Model includes birth weight, non-cardiac congenital anomalies, birth year, site, sex, plurality, maternal race/ethnicity, and county deprivation tertile at birth

#Model includes plurality, birth year, site, sex, and maternal race/ethnicity

**Model includes maternal race/ethnicity, birth year, and site

††Model includes county deprivation tertile at birth, birth year, site, and maternal race/ethnicity

‡‡Model includes rurality of birth county, birth year, site, maternal race/ethnicity, and county deprivation tertile at birth

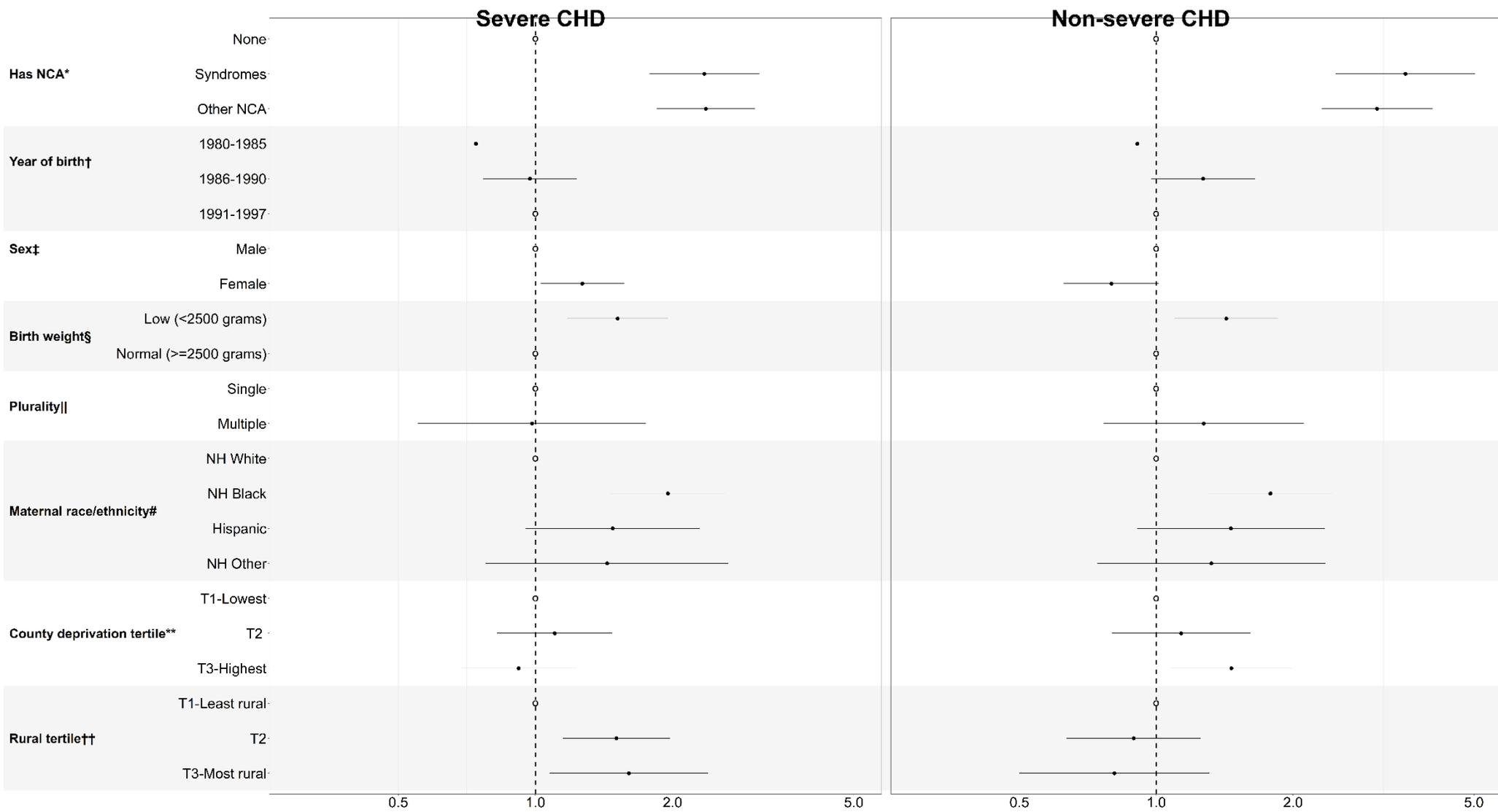
Supplemental Table 4. Standardized mortality ratios for individuals with CHD compared to age group-, sex-, year-, race/ethnicity-, and site-matched data from the general US population, CH STRONG and NVSS – excluding those with non-cardiac congenital anomalies

	In the first year of life		Between 1 and 35 years of age	
	N deaths in CH STRONG	SMR (95% CI)	N deaths in CH STRONG	SMR (95% CI)
Total	518	7.18 (6.53, 7.88)	150	1.91 (1.62, 2.23)
CHD Severity				
Severe	382	18.06 (16.20, 20.08)	88	3.66 (2.96, 4.49)
Non-severe	136	2.38 (1.94, 2.88)	62	1.13 (0.88, 1.44)
Race/ethnicity				
White	322	8.26 (7.32, 9.29)	86	1.72 (1.38, 2.12)
Black	165	6.60 (5.56, 7.78)	52	2.47 (1.87, 3.22)
Sex				
Male	299	7.57 (6.68, 8.55)	73	1.38 (1.09, 1.73)
Female	219	6.68 (5.75, 7.73)	77	2.97 (2.36, 3.69)

CH STRONG= Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG, CHD= Congenital Heart Defect, NVSS =

National Vital Statistics System, SMR = Standardized Mortality Ratio

Supplemental Figure 1. Adjusted hazards ratios up to 35 years of age for individuals with CHD born between 1980 and 1997, conditional on survival beyond the first year of life, CH STRONG multiply imputed data – by CHD severity



CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being, CHD = Congenital Heart Defect; NCA = Non-Cardiac Congenital Anomalies; NH = Non-Hispanic; T = Tertile; O denotes reference group

*Model includes non-cardiac congenital anomalies, birth year, site, sex, plurality, maternal race/ethnicity, and county deprivation tertile at birth

†Model includes birth year and site

‡Model includes sex and birth year

§Model includes birth weight, non-cardiac congenital anomalies, birth year, site, sex, plurality, maternal race/ethnicity, and county deprivation tertile at birth

||Model includes plurality, birth year, site, sex, and maternal race/ethnicity

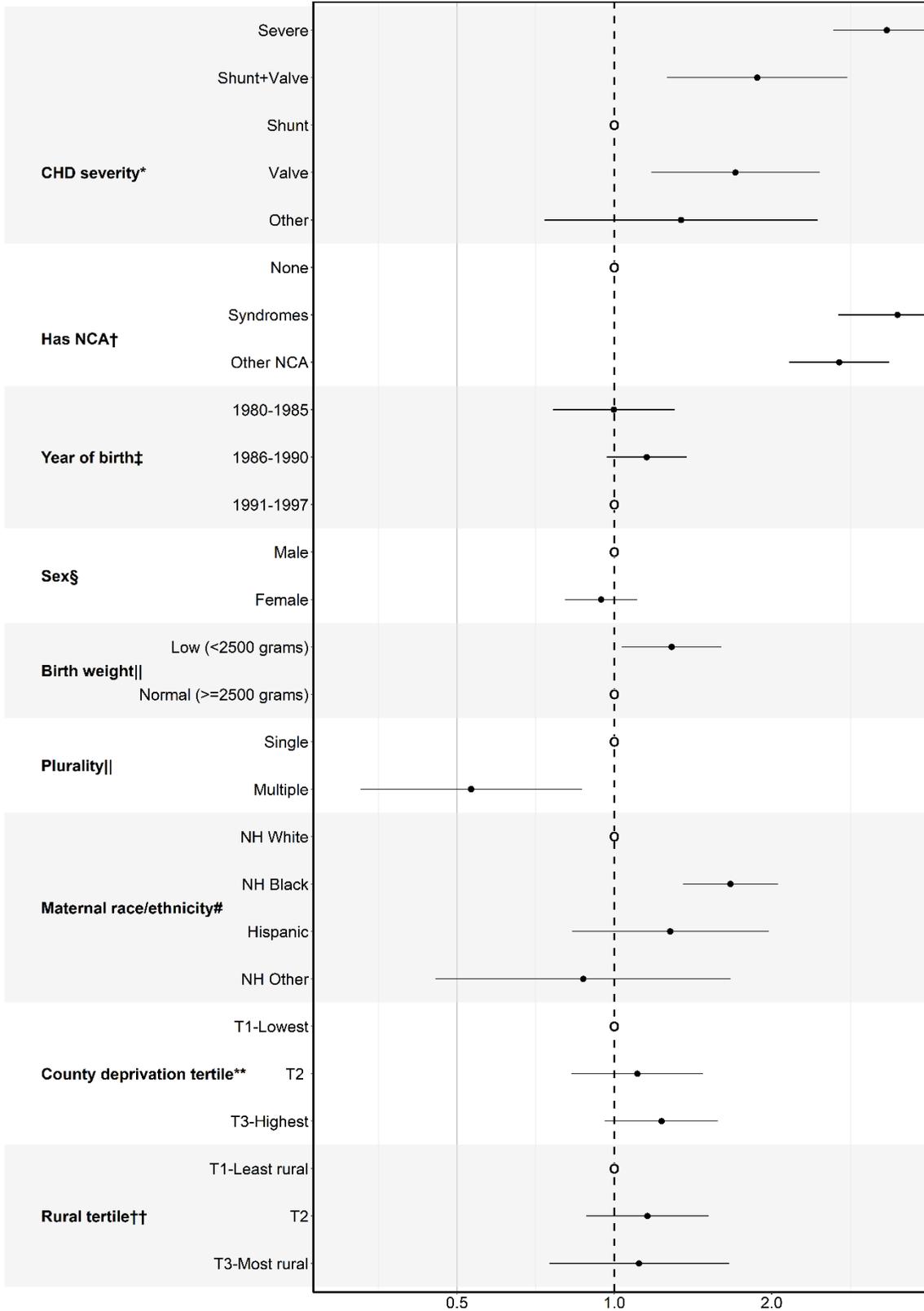
#Model includes maternal race/ethnicity, birth year, and site

**Model includes county deprivation tertile at birth, birth year, site, and maternal race/ethnicity

††Model includes rurality of birth county, birth year, site, and maternal race/ethnicity, site, and county deprivation tertile at birth

Supplemental Figure 2. Adjusted hazards ratios up to 35 years of age for individuals with CHD born between 1980 and 1997, conditional on survival beyond the first year of life, CH

STRONG – complete case analyses



CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being,

CHD = Congenital Heart Defect; NCA = Non-Cardiac Congenital Anomalies; NH = Non-

Hispanic; T = Tertile; O denotes reference group

*Model includes CHD severity, non-cardiac congenital anomalies, birth year, site, sex, maternal race/ethnicity, and county deprivation tertile at birth

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‡Model includes birth year and site

§Model includes sex and birth year

||Model includes birth weight, non-cardiac congenital anomalies, birth year, site, sex, plurality, maternal race/ethnicity, and county deprivation tertile at birth

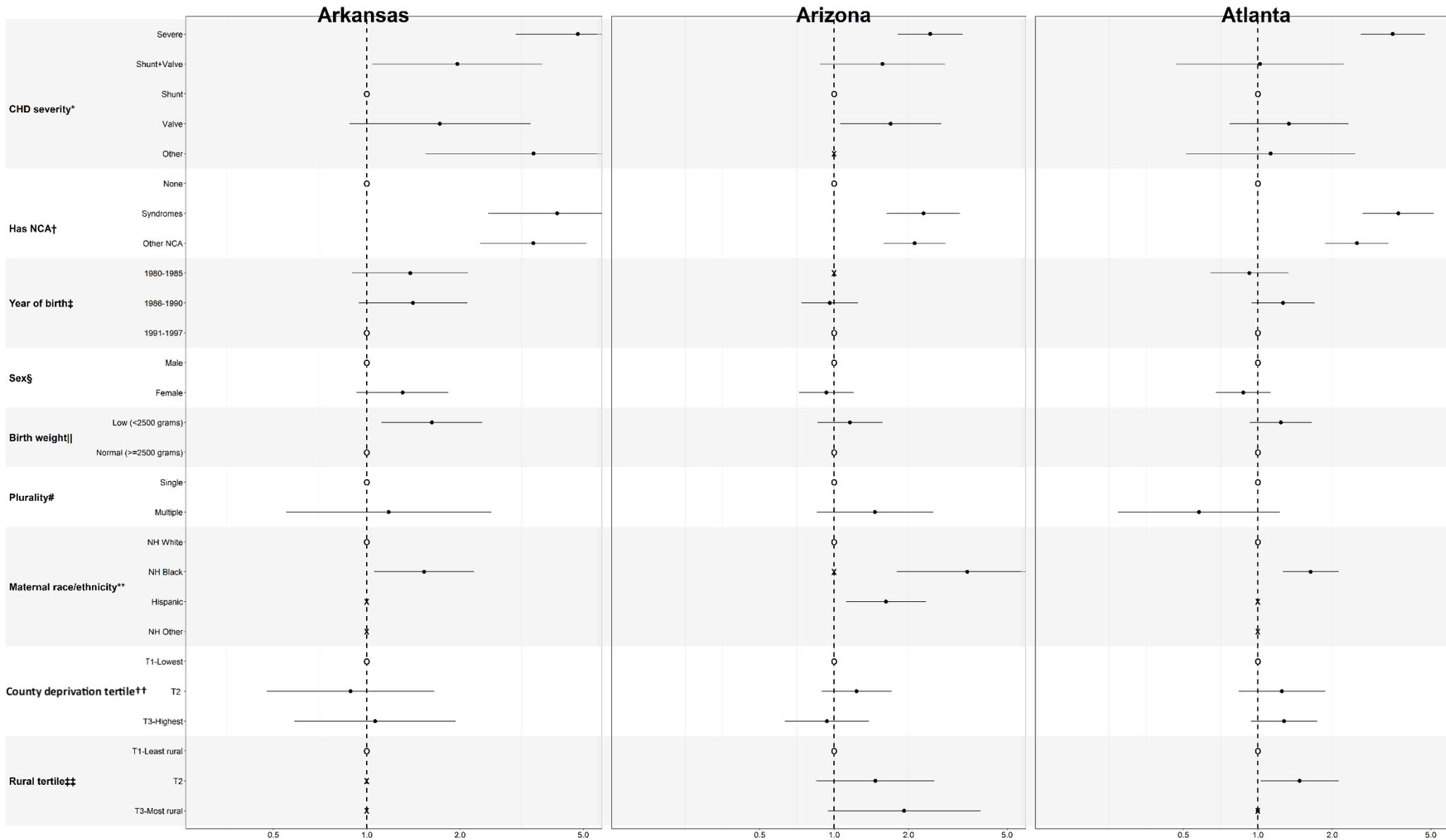
#Model includes plurality, birth year, site, sex, and maternal race/ethnicity

**Model includes maternal race/ethnicity, birth year, and site

††Model includes county deprivation tertile at birth, birth year, site, and maternal race/ethnicity

‡‡Model includes rurality of birth county, birth year, site, maternal race/ethnicity, and county deprivation tertile at birth

Supplemental Figure 3. Adjusted hazards ratios up to 35 years of age for individuals with CHD born between 1980 and 1997, conditional on survival beyond the first year of life, CH STRONG multiply imputed data – by site



CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being, CHD = Congenital Heart Defect; NCA = Non-Cardiac Congenital Anomalies; NH = Non-Hispanic; T = Tertile; O denotes reference group

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‡Model includes birth year and site

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||Model includes birth weight, non-cardiac congenital anomalies, birth year, site, sex, plurality, maternal race/ethnicity, and county deprivation tertile at birth

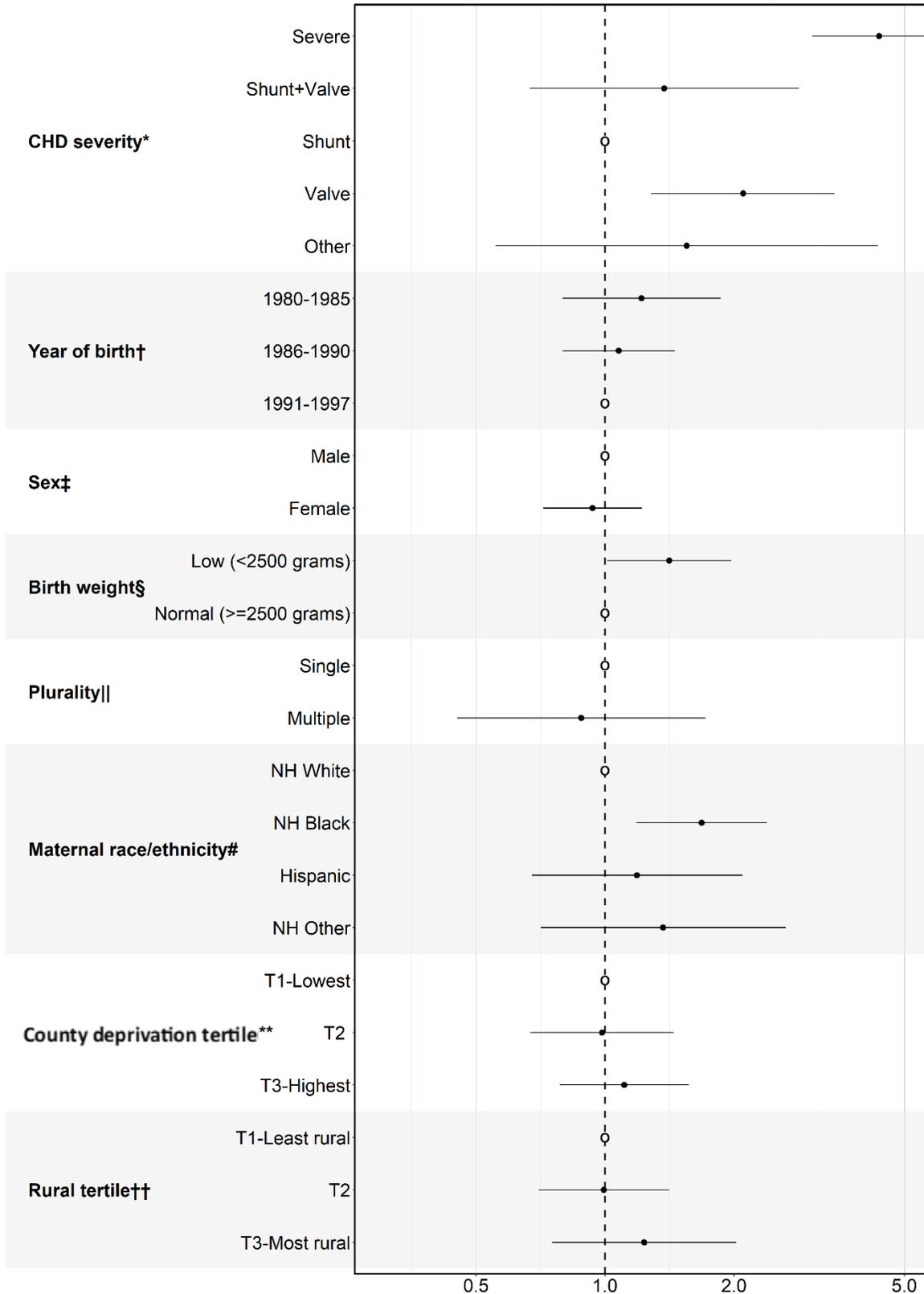
#Model includes plurality, birth year, site, sex, and maternal race/ethnicity

**Model includes maternal race/ethnicity, birth year, and site

††Model includes county deprivation tertile at birth, birth year, site, and maternal race/ethnicity

‡‡Model includes rurality of birth county, birth year, site, maternal race/ethnicity, and county deprivation tertile at birth

Supplemental Figure 4. Adjusted hazards ratios up to 35 years of age for individuals with CHD born between 1980 and 1997, conditional on survival beyond the first year of life, CH STRONG multiply imputed data – excluding those with non-cardiac congenital anomalies



CH STRONG = Congenital Heart Survey To Recognize Outcomes, Needs, and well-being,

CHD = Congenital Heart Defect; NH = Non-Hispanic; T = Tertile; O denotes reference group

*Model includes CHD severity, birth year, site, sex, maternal race/ethnicity, and county deprivation tertile at birth

†Model includes birth year and site

‡Model includes sex and birth year

§Model includes birth weight, birth year, site, sex, plurality, maternal race/ethnicity, and county deprivation tertile at birth

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