Appendix 1. Characteristics of individuals included and excluded from the analysis due to missing data on variables of interest, CH STRONG, 2016-2019

|  | **Missing data** | | **Not missing data** | | **Chi-square p-value** |
| --- | --- | --- | --- | --- | --- |
|  | N | % | N | % |  |
| **Total** | 115 | 6.9 | 1541 | 93.1 |  |
| **Advance care directive** |  |  |  |  | 0.4681 |
| Yes | 3 | 4.3 | 127 | 8.2 |  |
| No | 64 | 91.4 | 1338 | 86.8 |  |
| DK/NS | 3 | 4.3 | 76 | 4.9 |  |
| Missing | 45 |  | 0 |  |  |
| **Site** |  |  |  |  | 0.2219 |
| AR | 45 | 39.1 | 587 | 35.5 |  |
| AZ | 28 | 24.4 | 484 | 31.4 |  |
| GA | 42 | 36.5 | 470 | 30.5 |  |
| **CHD severity** |  |  |  |  | 0.4268 |
| Severe | 35 | 30.4 | 525 | 34.1 |  |
| Non-severe | 80 | 69.6 | 1016 | 65.9 |  |
| **Age at survey completion** |  |  |  |  | 0.2585 |
| 19-24 | 50 | 43.5 | 670 | 43.5 |  |
| 25-30 | 40 | 34.8 | 620 | 40.2 |  |
| 31-38 | 25 | 21.7 | 251 | 16.3 |  |
| **Sex** |  |  |  |  | 0.8336 |
| Male | 54 | 47 | 708 | 45.9 |  |
| Female | 61 | 53 | 833 | 54.1 |  |
| **Race/ethnicity** |  |  |  |  | 0.1426 |
| Hispanic | 12 | 14.1 | 161 | 10.4 |  |
| NH White | 49 | 57.7 | 1073 | 69.6 |  |
| NH Black | 16 | 18.8 | 203 | 13.2 |  |
| Multi / Other | 8 | 9.4 | 104 | 6.7 |  |
| Missing | 30 |  | 0 |  |  |
| **Insurance type** |  |  |  |  | 0.0001 |
| Private, no public | 30 | 30.3 | 765 | 51.3 |  |
| Public | 35 | 35.4 | 419 | 28.1 |  |
| None/other | 34 | 34.3 | 308 | 20.6 |  |
| Missing | 16 |  | 49 |  |  |
| **Non-cardiac congenital anomalies** |  |  |  |  | 0.4252 |
| Yes | 44 | 38.3 | 533 | 34.6 |  |
| No | 71 | 61.7 | 1008 | 65.4 |  |
| **Ever married** |  |  |  |  | 0.4143 |
| Is or has been married | 19 | 21.8 | 397 | 25.8 |  |
| Never married | 68 | 78.2 | 1144 | 74.2 |  |
| Missing | 28 |  | 0 |  |  |
| **Education** |  |  |  |  | 0.0617 |
| ≤High school | 38 | 47.5 | 572 | 37.1 |  |
| >High school | 42 | 52.5 | 969 | 62.9 |  |
| Missing | 35 |  | 0 | 0 |  |
| **Number of disabilities** |  |  |  |  | <.0001 |
| 0 | 23 | 34.9 | 934 | 60.6 |  |
| ≥1 | 43 | 65.2 | 607 | 39.4 |  |
| Missing | 49 |  | 0 |  |  |
| **Number of cardiac comorbidities** |  |  |  |  | 0.6928 |
| 0 | 84 | 85.7 | 1303 | 87.1 |  |
| ≥1 | 14 | 14.3 | 193 | 12.9 |  |
| Missing | 17 |  | 45 |  |  |
| **Ever had heart failure** |  |  |  |  |  |
| Yes | 4 | 4.1 | 69 | 4.6 | 0.8077 |
| No | 94 | 95.9 | 1427 | 95.4 |  |
| Missing | 17 |  | 45 |  |  |
| **Number of healthcare visits in last year** |  |  |  |  |  |
| 0 | 21 | 22.3 | 274 | 17.9 | 0.2738 |
| ≥1 | 73 | 77.7 | 1260 | 82.1 |  |
| Missing | 21 |  | 7 |  |  |
| **Number of hospitalizations in last year** |  |  |  |  | 0.3045 |
| 0 | 74 | 84.1 | 1353 | 87.8 |  |
| ≥1 | 14 | 15.9 | 188 | 12.2 |  |
| Missing | 27 |  | 0 |  |  |
| **Cardiology care in last 24 months** |  |  |  |  | 0.3449 |
| Yes | 48 | 52.2 | 726 | 47.1 |  |
| No | 44 | 47.8 | 815 | 52.9 |  |
| Missing | 23 |  | 0 |  |  |
| **Ever had a live birth \*** |  |  |  |  | 0.1267 |
| Yes | 19 | 39.6 | 236 | 29.2 |  |
| No | 29 | 60.4 | 572 | 70.8 |  |
| Missing | 13 |  | 25 |  |  |
| **Concern about future health** |  |  |  |  | 0.5902 |
| Not at all | 20 | 25.0 | 325 | 21.3 |  |
| Not very | 18 | 22.5 | 423 | 27.7 |  |
| Somewhat | 25 | 31.3 | 511 | 33.4 |  |
| Very | 17 | 21.3 | 269 | 17.6 |  |
| Missing | 35 |  | 13 |  |  |
| **Concern about heart health** |  |  |  |  | 0.2526 |
| Not at all | 18 | 22.5 | 343 | 22.3 |  |
| Not very | 17 | 21.3 | 458 | 30.1 |  |
| Somewhat | 27 | 33.8 | 478 | 31.4 |  |
| Very | 18 | 22.5 | 244 | 16.0 |  |
| Missing | 35 |  | 18 |  |  |
| **Perceived health status** |  |  |  |  | <.0001 |
| Excellent | 15 | 15.0 | 250 | 16.3 |  |
| Very good | 22 | 22.0 | 550 | 35.9 |  |
| Good | 33 | 33.0 | 521 | 34.0 |  |
| Fair | 23 | 23.0 | 188 | 12.3 |  |
| Poor | 7 | 7.0 | 23 | 1.5 |  |
| Missing | 15 |  | 9 |  |  |

AR: Arkansas; AZ: Arizona; CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; CHD: congenital heart defect; DK/NS: don’t know/not sure; GA: metropolitan-Atlanta, GA; NH: non-Hispanic

\*Females only