Supplemental Table 1. Comparing women excluded from and included in the analysis based on missing data on variables of interest, CH STRONG, 2016-2019

|  | | *Missing data* | | *Not missing data* | |  |
| --- | --- | --- | --- | --- | --- | --- |
| *Characteristic* | *levels* | *N* | *Percent* | *N* | *Percent* | *P-value* |
| Total |  | 116 | 100 | 778 | 100 | . |
| Age at survey completion | 19-24 | 57 | 49.1 | 318 | 40.9 | 0.15 |
|  | 25-30 | 38 | 32.8 | 326 | 41.9 | . |
|  | 31-38 | 21 | 18.1 | 134 | 17.2 | . |
| CHD severity | Non-severe | 75 | 64.7 | 557 | 71.6 | 0.13 |
|  | Severe | 41 | 35.3 | 221 | 28.4 | . |
| Race/ethnicity | Hispanic | 16 | 16.2 | 75 | 9.6 | 0.16 |
|  | NH White | 57 | 57.6 | 521 | 67 | . |
|  | NH Black | 19 | 19.2 | 129 | 16.6 | . |
|  | Multi / Other | 7 | 7.1 | 53 | 6.8 | . |
|  | Missing | 17 | . | . | . | . |
| Presence of chromosomal anomalies | Yes | 14 | 12.1 | 71 | 9.1 | 0.31 |
|  | No | 102 | 87.9 | 707 | 90.9 | . |
| Place of birth | Arizona | 39 | 33.6 | 198 | 25.4 | 0.18 |
|  | Arkansas | 42 | 36.2 | 317 | 40.7 | . |
|  | Georgia | 35 | 30.2 | 263 | 33.8 | . |
| Education | <High school | 14 | 15.2 | 50 | 6.4 | 0.008 |
|  | =High school | 24 | 26.1 | 204 | 26.2 | . |
|  | >High school | 54 | 58.7 | 524 | 67.4 | . |
|  | Missing | 24 | . | . | . | . |
| Insurance Type | Any Private | 40 | 36 | 415 | 53.3 | 0.002 |
|  | Public | 32 | 28.8 | 178 | 22.9 | . |
|  | Other, None, or DKNS | 39 | 35.1 | 185 | 23.8 | . |
|  | Missing | 5 | . | . | . | . |
| Receipt of healthcare in last 12 months | Yes | 80 | 79.2 | 672 | 86.4 | 0.05 |
|  | No | 21 | 20.8 | 106 | 13.6 | . |
|  | Missing | 15 | . | . | . | . |
| Most recent cardiology care | ≤2 years | 57 | 54.8 | 357 | 45.9 | 0.19 |
|  | 3-5 years | 7 | 6.7 | 80 | 10.3 | . |
|  | >5 years or never | 40 | 38.5 | 341 | 43.8 | . |
|  | Missing | 12 | . | . | . | . |
| Concerned about ability to have children | Yes | 67 | 74.4 | 508 | 65.3 | . |
|  | No | 23 | 25.6 | 270 | 34.7 | 0.08 |
|  | Missing | 26 | . | . | . | . |
| Clinician discussion about special concerns about becoming pregnant | Yes | 26 | 31 | 239 | 30.7 | 0.97 |
|  | No | 58 | 69 | 539 | 69.3 | . |
|  | Missing | 32 | . | . | . | . |
| Clinician advice to avoid pregnancy because of heart problem | Yes | 15 | 18.3 | 104 | 13.4 | 0.22 |
|  | No | 67 | 81.7 | 674 | 86.6 | . |
|  | Missing | 34 | . | . | . | . |
| Ever married | 0 | 68 | 70.1 | 558 | 71.7 | 0.74 |
|  | ≥1 | 29 | 29.9 | 220 | 28.3 | . |
|  | Missing | 19 | . | . | . | . |
| Ever pregnant | Yes | 32 | 38.6 | 266 | 34.2 | 0.43 |
|  | No | 51 | 61.4 | 512 | 65.8 | . |
|  | Missing | 33 | . | . | . | . |
| Clinician counseling on safe contraceptive methods | Yes | 20 | 24.1 | 178 | 22.9 | 0.80 |
|  | No | 63 | 75.9 | 600 | 77.1 | . |
|  | Missing | 33 | . | . | . | . |
| Delay or avoided pregnancy because of concerns about your heart health | Yes | 12 | 16.4 | 116 | 14.9 | 0.73 |
|  | No | 61 | 83.6 | 662 | 85.1 | . |
|  | Missing | 43 | . | . | . | . |
| ≥1 Disabilities | Yes | 45 | 55.6 | 323 | 41.5 | 0.02 |
|  | No | 36 | 44.4 | 455 | 58.5 | . |
|  | Missing | 35 | . | . | . | . |
| Hearing | Yes | 8 | 7.8 | 37 | 4.8 | 0.19 |
|  | No | 95 | 92.2 | 741 | 95.2 | . |
|  | Missing | 13 | . | . | . | . |
| Vision | Yes | 10 | 9.7 | 43 | 5.5 | 0.09 |
|  | No | 93 | 90.3 | 735 | 94.5 | . |
|  | Missing | 13 | . | . | . | . |
| Mobility | Yes | 20 | 20.4 | 100 | 12.9 | 0.04 |
|  | No | 78 | 79.6 | 678 | 87.1 | . |
|  | Missing | 18 | . | . | . | . |
| Cognition | Yes | 33 | 35.1 | 241 | 31 | 0.42 |
|  | No | 61 | 64.9 | 537 | 69 | . |
|  | Missing | 22 | . | . | . | . |
| Self-care | Yes | 14 | 13.6 | 53 | 6.8 | 0.02 |
|  | No | 89 | 86.4 | 725 | 93.2 | . |
|  | Missing | 13 | . | . | . | . |
| Living independently | Yes | 33 | 33.3 | 175 | 22.5 | 0.02 |
|  | No | 66 | 66.7 | 603 | 77.5 | . |
|  | Missing | 17 | . | . | . | . |
| Proxy report | Yes | 29 | 28.2 | 118 | 15.2 | 0.001 |
|  | No | 74 | 71.8 | 660 | 84.8 | . |
|  | Missing | 13 | . | . | . | . |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG

**Sensitivity Analyses**

**Sensitivity analysis 1: Excluding women with proxy report**

**Table 2.A. Clinician counseling about reproductive health issues among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women with proxy reports***

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | | On safe contraceptive methods | | About special concerns about becoming pregnant | | Advice to avoid pregnancy because of heart problem | |
|  |  | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) |
| ≥ 1 disability | Yes | 27.1 (21.8,33.3) | 1.45 (1.1,1.92) | 34.8 (29.6, 40.4) | 1.21 (0.98,1.49) | 20.3 (16.1,25.1) | 2.44 (1.64,3.64) |
|  | No | 19.4 (16.4,22.7) |  | 29.3 (26.5, 32.4) |  | 7.5 (5.6,10) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Table 2.B. Reproductive health concerns and outcomes among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women with proxy reports***

|  | | Concern about ability to have children | | Delayed or avoided pregnancy because of concerns about heart health | | Ever pregnant | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | | aPR2 (95% CI) |
| ≥ 1 disability | Yes | 43.5 (36.9,50.3) | 1.40 (1.14,1.71) | 19.6 (15.3,24.8) | 2.18 (1.52,3.13) | 39.8 (33.8,46.1) | 0.89 (0.73,1.08) | |
|  | No | 32.0 (27.6,36.9) |  | 8.8 (6.6,11.7) |  | 40.1 (35.7,44.6) | |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Sensitivity analysis 2: Excluding women with chromosomal anomalies**

**Table 3.A. Clinician counseling about reproductive health issues among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women with chromosomal anomalies***

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | | On safe contraceptive methods | | About special concerns about becoming pregnant | | Advice to avoid pregnancy because of heart problem | |
|  |  | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) |
| ≥ 1 disability | Yes | 26.2 (21.4,31.6) | 1.52 (1.16,1.98) | 32.2 (27.7, 37.0) | 1.20 (0.98,1.48) | 21.3 (17.4,25.8) | 2.75 (1.86,4.07) |
|  | No | 18.5 (15.4,22.1) |  | 27.9 (24.9, 31.2) |  | 7.1 (5.2,9.6) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Table 3.B. Reproductive health concerns and outcomes among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women with chromosomal anomalies***

|  | | Concern about ability to have children | | Delayed or avoided pregnancy because of concerns about heart health | | Ever pregnant | |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) |
| ≥ 1 disability | Yes | 40.9 (34.8,47.3) | 1.36 (1.11,1.66) | 21.2 (16.8,26.4) | 2.35 (1.65,3.35) | 36.3 (30.7,42.3) | 0.83 (0.68,1.02) |
|  | No | 31.3 (27.1,35.8) |  | 8.7 (6.5,11.6) |  | 40.6 (36.4,44.9) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Sensitivity analysis 3: Excluding women without a healthcare visit in the last 12 months**

**Table 4.A. Clinician counseling about reproductive health issues among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women without a healthcare visit in the last 12 months***

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | | | On safe contraceptive methods | | About special concerns about becoming pregnant | | Advice to avoid pregnancy because of heart problem | |
|  |  | | Standardized %1 (95% CI) | | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) |
| ≥1 disability | | Yes | | 24.4 (19.9,29.5) | 1.32 (1.00,1.74) | 28.9 (24.3,34) | 1.06 (0.86,1.32) | 17.6 (13.9,21.9) | 2.16 (1.44,3.24) |
|  | | No | | 18.6 (15.3,22.4) |  | 27.7 (24.5,31.2) |  | 7.6 (5.8,10.0) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Table 4.B. Reproductive health concerns and outcomes among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women without a healthcare visit in the past 12 months***

|  | | Concern about ability to have children | | Delayed or avoided pregnancy because of concerns about heart health | | Ever pregnant | |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) |
| ≥ 1 disability | Yes | 36.5 (30.9,42.5) | 1.22 (0.99,1.50) | 19.9 (15.6,25.0) | 2.12 (1.47,3.04) | 28.9 (23.8,34.5) | 0.70 (0.56,0.89) |
|  | No | 33.4 (28.6,38.6) |  | 8.5 (6.3,11.4) |  | 39.8 (35.1,44.8) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Sensitivity analysis 4: Excluding women without a cardiology visit in the past 5 years**

**Table 5.A. Clinician counseling about reproductive health issues among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women without a cardiology visit in the past 5 years***

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | | On safe contraceptive methods | | About special concerns about becoming pregnant | | Advice to avoid pregnancy because of heart problem | |
|  |  | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) |
| ≥1 disability | Yes | 32.0 (25.6,39.2) | 1.24 (0.95,1.62) | 39.9 (33.3,47.0) | 0.94 (0.77,1.15) | 24.9 (19.3,31.4) | 2.06 (1.41,3.01) |
|  | No | 25.6 (20.7,31.1) |  | 43.0 (36.8,49.5) |  | 10.7 (7.8,14.4) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Table 5.B. Reproductive health concerns and outcomes among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; *excluding women without any cardiology visit in the past five years***

|  | | Concern about ability to have children | | Delayed or avoided pregnancy because of concerns about heart health | | Ever pregnant | |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) | Standardized %1 (95% CI) | aPR2 (95% CI) |
| ≥ 1 disability | Yes | 45.0 (38.0,52.3) | 1.28 (1.02,1.60) | 29.0 (22.8,36.0) | 1.95 (1.36,2.79) | 23.8 (18.5,30.1) | 0.72 (0.53,0.96) |
|  | No | 36.0 (29.6,42.9) |  | 12.3 (8.8,17.0) |  | 39.2 (33.1,45.6) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Sensitivity analysis 5: Stratifying results by marital status**

**Table 6.A. Clinician counseling about reproductive health issues among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; Stratified by marital status**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | Ever married women | | | | | | Never married women | | | | | |
|  | | On safe contraceptive methods | | About special concerns about becoming pregnant | | Advice to avoid pregnancy because of heart problem | | On safe contraceptive methods | | About special concerns about becoming pregnant | | Advice to avoid pregnancy because of heart problem | |
|  |  | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI)1 | aPR2 (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) |
| ≥ 1 disability | Yes | 32.5  (23.3,43.3) | 1.49  (0.89,2.49) | 33.6  (28.1, 39.6) | 1.21  (0.85,1.72) | 21.7  (17.6, 26.5) | 4.11  (2.2,7.69) | 20.8  (16.5,25.8) | 1.44  (1.03,2.00) | 24.8  (20.3,29.9) | 1.44  (1.03,2.00) | 16.7  (12.6,21.7) | 2.13  (1.33,3.41) |
|  | No | 23.8  (16.9,32.4) |  | 29.8  (24.6, 35.6) |  | 5.7  (3.3, 9.7) |  | 16.0  (12.7,20.0) |  | 24.2  (20.7,28.2) |  | 9.1  (6.7,12.2) |  |

CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance

**Table 6.B. Reproductive health concerns and outcomes among women with congenital heart defects, by disability status, CH STRONG, 2016-2019; Stratified by marital status**

|  | | Ever married women | | | | | | Never married women | | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | Concern about ability to have children | | Delayed or avoided pregnancy because of concerns about heart health | | Ever pregnant | | Concern about ability to have children | | Delayed or avoided pregnancy because of concerns about heart health | | Ever pregnant | |
|  |  | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI) | aPR  (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) | Standardized %1  (95% CI) | aPR2  (95% CI) |
| ≥ 1 disability | Yes | 27.4  (18.3,38.9) | 1.51  (0.93,2.45) | 20.3  (14.0,28.6) | 1.87  (0.97,3.59) | 71.2  (60.8,79.9) | 0.92  (0.76,1.11) | 36.5  (30.8,42.6) | 1.16  (0.94,1.44) | 19.3  (14.9,24.6) | 2.94  (1.82,4.74) | 19.2  (14.9,24.3) | 0.81  (0.57,1.14) |
|  | No | 28.3  (21.7,35.9) |  | 15.1  (9.8,22.7) |  | 70.6  (63.0,77.1) |  | 35.9  (30.5,41.7) |  | 5.7  (3.6,9.0) |  | 22.5  (18.0,27.6) |  |

aPR: adjusted prevalence ratio; CI: confidence interval

1Standardized to the birth year, maternal race/ethnicity, site, and CHD severity of the CH STRONG- eligible female population

2Adjusted for CHD severity, age, state of birth, race/ethnicity, type of health insurance