

About CH STRONG

Since 2016, five teams of researchers have worked together on CH STRONG, the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG, to gather information to help improve the lives of people living with heart defects. We thank everyone who provided information for CH STRONG.

In the last CH STRONG newsletter, we reported that over 1,600 individuals living with heart defects participated in CH STRONG. We are excited to share the results of two new publications on the physical and mental health of young adults with heart defects, as well as their use of advance care directives, also known as living wills.

The next topics we will explore are quality of life, disability, healthcare use, education and work history, and reproductive health.

On the next page, you will find highlights from the recent publications mentioned above.

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Inside This Issue

"Comorbidities Among Young Adults with Congenital Heart Defects: Results from the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG – Arizona, Arkansas, and Metropolitan Atlanta, 2016–2019" published in Morbidity and Mortality Weekly Report (MMWR).

"Advance Care Directives Among a Population-Based Sample of Young Adults with Congenital Heart Defects, CH STRONG, 2016-2019" published in Pediatric Cardiology.



Physical and Mental Health of Young Adults with Heart Defects

After comparing CH STRONG data to national surveys of the general population, CH STRONG researchers found

Young adults living with heart defects were more likely than the general population to report additional cardiovascular issues such as...



Heart Failure

&



Stroke

as well as...



Symptoms of Depression

Young adults living with *severe* heart defects were more likely to have additional cardiovascular health issues than young adults living with *non-severe* heart defects.

Heart defects are lifelong conditions that require ongoing specialty medical care. It is important for people with heart defects to talk with a heart doctor, or cardiologist, regularly to make the best possible choices for their health.

Use of Advance Care Directives among Young Adults with Heart Defects

Many adults with heart defects live long, healthy lives, yet adults *with* heart defects are still more likely to die at younger ages than adults *without* heart defects. Advance care directives, or living wills, are legal documents in which people specify what actions to take for their health if they are no longer able to make decisions for themselves.

CH STRONG researchers found that only...



1 in 13

Young adults with heart defects had an advance care directive

&



1 in 10

Young adults with severe heart defects or heart failure had an advance care directive



Non-Hispanic Black Young Adults

&



Uninsured Young Adults

were less likely than other CH STRONG participants to have advance care directives

It is important to have a plan in place for end-of-life decisions. Creating advance care directives when young and healthy can ensure people receive end-of-life care according to their preferences. Adults with heart defects who do not have an advance care directive may want to consider talking to their doctor about their need to establish one.