

Survey ID

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Questions for Caretaker

Your Age

Your Gender Identity

- ☐ Male
- ☐ Female
- ☐ Non-binary/Third gender
- ☐ A gender not listed (please specify below)
- ☐ Unsure
- ☐ Prefer not to say

Your Race

Your Ethnicity

Your Level of Education

What is the primary language spoken at home?

- ☐ English
- ☐ Spanish
- ☐ English and Spanish
- ☐ Arabic
- ☐ Other
- ☐ Prefer not to say

Annual Household Income

How many people are in your household?

Do you have Internet at home?

- ☐ Yes
- ☐ No
- ☐ Unsure

Do you use a desktop computer, laptop or tablet?

- ☐ Yes
- ☐ No

Do you use a smart phone?

- ☐ Yes
- ☐ No

Questions About the Patient

What type of heart condition was your child diagnosed with? You may select more than one answer.

- ☐ Congenital Heart Disease
- ☐ Cardiomyopathy
- ☐ Cardiac Arrhythmia
- ☐ Unsure

What type of congenital heart disease was your child diagnosed with? You may select more than one answer.

- ☐ Ventricular Septal Defect
- ☐ Atrial Septal Defect
- ☐ Atrioventricular Canal Defect
- ☐ Ventricular Outflow Tract Obstruction
- ☐ Coarctation of the Aorta
- ☐ Vascular Ring
- ☐ Vascular Malformations
- ☐ Tetralogy of Fallot
- ☐ Transposition of the Great Arteries
- ☐ Single Ventricle Lesion
- ☐ Other

When was your child first diagnosed with a heart condition?

- ☐ Days ago
- ☐ Months ago
- ☐ Years ago (please specify number of years below)
-
- ☐ Unsure

Has your child had any surgeries or interventions for their heart condition?

- ☐ Yes (please specify the total number of surgeries and interventions
-
- below)
- ☐ No
- ☐ Unsure

Has your child ever been hospitalized for complications from their heart condition?

- ☐ Yes
- ☐ No
- ☐ Unsure

What type of medical insurance does your child have? You may select more than one answer.

☐ Uninsured

- ☐ Medicaid
- ☐ Child Health Plus (CHIP)
- ☐ Marketplace Exchange Plan
- ☐ TRICARE
- ☐ Employer-sponsored insurance (ESI)
- ☐ Other (please specify below)
- ☐ Unsure

Questions on Use of Informative Resources

What type(s) of resource(s) (if any) have you used **at least once** to learn about your child's heart condition? You may select more than one answer.

- ☐ Websites (e.g. WebMD)
- ☐ Social Media/Online Community (e.g. Facebook, Twitter)
- ☐ Video Sharing Platform (e.g. YouTube)
- ☐ Healthcare Professional (e.g. Pediatric cardiologist)
- ☐ Printed Sources (e.g. Textbook)
- ☐ Personal Network (e.g. Family members)
- ☐ None of the above
- ☐ Other

Which website(s) have you used **at least once** to learn about your

child's heart condition? You may select more than one answer.

- ☐ Commercial website (e.g. WebMD)
- ☐ Government website (e.g. CDC.gov)
- ☐ Hospital website
- ☐ Peer reviewed medical journal
- ☐ Website for national organization (e.g. Healthychildren.org)
- ☐ None of the above
- ☐ Other

Which social media site(s) and/or online communities have you used **at least once** to learn about your child's heart condition? You may select more than one answer.

- ☐ Facebook
- ☐ Reddit
- ☐ Twitter
- ☐ Instagram
- ☐ None of the above
- ☐ Other

Which video sharing platform(s) have you used **at least once** to learn about your child's heart condition? You may select more than one answer.

- ☐ YouTube

- ☐ Vimeo
- ☐ Daily Motion
- ☐ TikTok
- ☐ None of the above
- ☐ Other

Which health professional(s) have you consulted **at least once** to learn about your child's heart condition? You may select more than one answer.

- ☐ General Pediatrician (MD,DO)
- ☐ Pediatric Cardiologist (MD)
- ☐ Physician Assistant (PA)
- ☐ Nurse Practitioner (NP)
- ☐ Nurse (RN)
- ☐ None of the above
- ☐ Other

Please describe how your child's general pediatrician helped you learn about your child's heart condition.

Which type(s) of printed source(s) have you used **at least once** to learn about your child's heart condition? You may select more than one

answer.

- ☐ Pamphlets/Brochures
- ☐ Printed Medical Journal
- ☐ Textbook
- ☐ Chapterbook
- ☐ None of the above
- ☐ Other

Which individual(s) in your personal network have you consulted **at least once** to learn about your child's heart condition? You may select more than one answer.

- ☐ Family Member
- ☐ Friend
- ☐ Partner
- ☐ Religious Leader
- ☐ None of the above
- ☐ Other

Please mark any other resources you used **at least once** to learn about your child's heart condition. You may select more than one answer.

- ☐ Smart Phone Application (please write the application name below)
- ☐ Email

- ☐ WhatsApp
- ☐ None of the above
- ☐ Other

Which resource did you use most often?

- ☐ Websites
- ☐ Online Groups/Communities
- ☐ Video Sharing Platform
- ☐ Healthcare Professionals
- ☐ Print Sources
- ☐ Personal Network
- ☐ Other (please specify below)
- ☐ Not Applicable

How satisfied are you with the amount of information you have received about your child's heart condition?

- ☐ Extremely satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Extremely dissatisfied

How often do you have access to information in your native language?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

How often did the information you obtained agree with the doctors' recommendations?

- ☐ Always
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

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