

## Survey ID

Survey ID

## Patient Information

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

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

## Patient's Heart Condition

What type of heart condition were you diagnosed with? You may select more than one answer.

- ☐ Congenital Heart Disease

- ☐ Cardiomyopathy
- ☐ Cardiac Arrhythmia
- ☐ Unsure

What type of congenital heart disease were you 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 were you diagnosed with a heart condition?

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

Have you had any surgeries or interventions for your heart condition?

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

Have you ever been hospitalized because of your heart condition?

- ☐ Yes
- ☐ No
- ☐ Unsure

## Use of Resources

What type(s) of resource(s) (if any) have you used **at least once** to learn about your 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)

- ☐ Family and Friends
- ☐ None of the above
- ☐  Other (please specify below)

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

- ☐ Commercial website (e.g. WebMD, Healthline)
- ☐ Government website (e.g. CDC.gov)
- ☐ Hospital website
- ☐ Peer reviewed medical journal
- ☐ Website for a 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 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 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 or your parent(s) talked to **at least once** to learn about your 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 general pediatrician helped you learn about your heart condition.

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

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

Who have you talked to **at least once** to learn about your 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 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 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 your doctors' recommendations?

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

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