
YOUNG PEOPLE CONSUMER SURVEY: INFORMATIONS FOR TEENS AND PARENTS

At [HeartKids](#), we are working on a project as part of the [National Strategic Action Plan for Childhood Heart Disease](#) to engage with young people who have childhood heart disease and assist them to transition to ongoing adult care for their condition. To improve this process for teens and young people, we need to talk to them to find out more about their needs. This survey is the first stage in gathering this information for the current project.

Note: For the purpose of the survey when we refer to childhood heart disease it includes congenital heart disease and heart disease acquired during childhood.

How can I help?

If you are 12 – 25 years old and have a childhood heart condition, you can help by completing this survey about what it's like being a young person with childhood heart disease, how you like to receive health information and the type of information you seek.

The survey will be open until Monday 17 August 2020.

Who should complete this survey?

This survey is specifically designed to be completed by young people (12 – 25-year olds) who have a childhood heart condition. When completing the survey, you may ask a parent or carer for help to understand a question, however you should submit each response from your own perspective.

Note: If you are younger than 15, you will need permission from a parent or guardian to do this survey.

How long does the survey take to complete?

The survey should take approximately 15 minutes to complete.

What kinds of things does the survey ask?

The survey asks about many topics, including:

- How teens/young people currently manage remembering to take their medications
- How teens/young people feel about transferring to adult care
- How well teens/young people understand concepts like patient confidentiality
- How equipped teens/young people feel in accessing reliable health information online.

Can I skip a question?

You can skip a question at any time if you are unsure on the answer, don't see the question as being relevant to you, or if you feel uncomfortable answering it. A few questions are compulsory (just the ones asking you about your age and consent to complete the survey).

Important information for parents/guardians

Young people may have questions while doing the survey. We encourage you to sit with them and help them understand what certain questions mean if required. However, we ask that young people complete each response from their own perspective.

We encourage parents and families to complete our separate [Consumer Survey](#) to share their own views.

Note: 12 – 14-year olds complete a shorter version of the survey as not all the topic areas are relevant to or suitable for them. When they select their age group at the start of the survey they will be prompted for parental consent. If permission is given, they will be automatically redirected to the shorter survey.

This survey asks some personal questions. How does HeartKids protect my privacy?

All data attached to this survey will remain deidentified. This means we won't know who you are. To protect your privacy, we don't ask for any personal contact information in the survey.

Why does HeartKids have to ask about my gender, age and location?

We need this information so that we know what segments of our community we have collected responses from. We are seeking input from a broad range of people, from different age groups, locations and genders. These questions will not impact on your privacy and will not enable you to be identified.

What will HeartKids do with my data?

This data will provide insights on the information and support needs of teens and young people with childhood heart disease. It will help us to improve care for young Australians with these conditions. Deidentified data summaries may be shared with our key partners, such as the Department of Health, if it supports this objective.

How do I stay updated on this project and other HeartKids information?

We encourage all members of our community to subscribe for updates so that we can keep you across the work we're doing and the support we can offer. [Subscribe](#) to our newsletter to stay updated.

More information

If you have any questions about the survey, please contact: ask@heartkids.org.au