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## CONSUMER SURVEY: INFORMATION SHEET

At [HeartKids](#), we are working on a project as part of the [National Strategic Action Plan for Childhood Heart Disease](#) to create new resources for individuals and families impacted by childhood-onset heart disease. This survey is the first stage in gathering information from our community for this part of the project.

**Note:** For the purpose of the survey and this document, 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 impacted by childhood heart disease, you can help by completing this survey to tell us how you like to receive health information, the type of information you seek, and whether you've experienced any gaps when trying to find information or trying to understand and manage the impact of childhood heart disease.

The survey will be open until Monday 17 August 2020.

### Who should complete this survey?

Anyone who is impacted by childhood heart disease should complete this survey. This includes:

- People who have a childhood heart disease
- Parents, relatives or carers of someone with a childhood heart disease (including siblings, grandparents, aunts, uncles, cousins)
- Spouses or partners of someone with a childhood heart disease
- Bereaved parents, relatives or carers who have lost someone to childhood heart disease.

We expect the majority of responses on this survey to come from parents. We are also very interested in hearing from siblings and other family members. We strongly encourage parents to support siblings to complete the survey and to share the survey with other relevant family members and connections.

**Note for young people:** If you are a young person (12 – 25-year-old) with a childhood heart disease, you may already have completed our other youth-focused survey designed specifically for your group. There is no need to complete both surveys as many questions are repeated. Complete the [Young People Survey](#).

**Note for bereaved families:** If you are a bereaved parent or family member of a person who has passed away from childhood heart disease, please note that not all questions will relate directly to your loss however we ask if you could answer these other questions at the time you were looking for information on childhood heart disease.

### How long does the survey take to complete?

The survey takes approximately 15 minutes to complete.

### 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 and will not be able to be skipped as they determine which version of the next question you will get.

### **What kinds of things does the survey ask?**

The survey asks about many topics, including:

- Accessing support networks
- Understanding of financial support options
- Identifying issues with current childhood heart disease information
- Examining learning style preferences
- Testing current ideas for consumer resources

### **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 enable us to identify you and will not impact on your privacy.

### **What will HeartKids do with my data?**

This data will provide insights on the information and support needs of people impacted by childhood heart disease so that we can fix any current gaps. It will help us to improve the journey for Australians impacted by 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 informed with what HeartKids is doing?**

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](mailto:ask@heartkids.org.au)