

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of this study?

The ultimate purpose of this study is to find better ways to support survivors by improving long term follow-up services.

Why have I been invited to participate in this study?

You have been invited to participate in this study because you are a child of a child who has had a cancer diagnosis. We are looking for children who are aged 18 years or older and who have not had any contact with the research team since their diagnosis. We are looking for children who are currently living in Australia and who are able to provide their own consent to participate in the study.

What if I don't want to take part in this study, or if I want to withdraw later?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. It will not affect your relationship with the staff caring for you. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

What does this study involve?

If you agree to participate, you will be asked to participate in an online consultation with the hospital's Clinical Nurse Consultant, held at a time convenient for you. The consultation is free to you, and is delivered online through a web-based audio-visual software called Skype. The content of the consultation will match that of a face-to-face nurse-led visit to the long term follow-up clinic. The consultation will take approximately 50-60 minutes, although this may vary for each person.

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Are there risks to me in taking part in this study?

It is possible that thinking about your child's health and the related emotions you have experienced may cause you to feel worried or upset. The research team will be available to talk about any worries or concerns you may have. You can contact us by calling T 08 9382 3111. Any questions or concerns that arise about your health can also be answered by your doctor.

Will I benefit from the study?

There is a possibility that you will benefit from the study. The research team will be available to talk about any worries or concerns you may have. You can contact us by calling T 08 9382 3111. Any questions or concerns that arise about your health can also be answered by your doctor.

Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything. You will not be paid for your participation. The research team will be available to talk about any worries or concerns you may have. You can contact us by calling T 08 9382 3111. Any questions or concerns that arise about your health can also be answered by your doctor.

How will my confidentiality be protected?

Only the research staff directly involved in this study will know whether or not you are participating in this study and have access to your data. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Data will be held securely at Sydney Children's Hospital.

What happens with the results?

We plan to share the results of the study with the Human Research Ethics Committee (HREC) for ethical monitoring purposes and in peer-reviewed journals and at conferences or other professional forums for the promotion of knowledge in the health services. When published, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, via the Behavioural Sciences Unit newsletter and website.

How is this study being paid for?

The study is being supported by the Kids Cancer Research Foundation. The research team will be available to talk about any worries or concerns you may have. You can contact us by calling T 08 9382 3111. Any questions or concerns that arise about your health can also be answered by your doctor.

Do I have to sign a separate consent form?

You will need to sign a separate consent form. The research team will be available to talk about any worries or concerns you may have. You can contact us by calling T 08 9382 3111. Any questions or concerns that arise about your health can also be answered by your doctor.

