


<p>Kids Cancer Centre Sydney Children Hospital The University of New South Wales</p>	
<p><b>Online participant information statement and consent form</b></p> <p>Evaluating health behaviours and beliefs in childhood cancer survivors (CCS), adult cancer survivors (ACS) and healthy Australians</p>	

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 purpose of this study is to investigate health issues, health-behaviour, life style, health literacy and beliefs and attitudes towards new medical technologies in the Australian population.

**‘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. Continuing the survey indicates that you have read and understood this information, that you willingly agree to participate. You may withdraw your consent at any time without penalty and you are not waiving legal claims. To do that you need to leave the survey before submitting your answers at the end of the survey. As the data are collected anonymously, once you have submitted your answers your data will not be identifiable. As there is no way to identify your responses in the data, they cannot be excluded from future analysis.

You may print this screen for your records.

**‘What does this study involve?’**

If you agree to participate in this study, you will be asked to complete an online questionnaire which will take approximately 25-30 minutes.

**‘How is this study being paid for?’**

The study is being supported by the Behavioural Sciences Unit, Kids Cancer Centre, and Kids with Cancer Foundation.

**‘Are there risks to me in taking part in this study?’**

We do not anticipate any risks of harm or discomfort which may be physical, psychological, social, cultural or financial. However if you feel any distress, you may withdraw from the survey at any time, without stating a reason. The research team will be available to talk about any worries or concerns you may have. You can contact us by calling the free telephone number 1800 990 056.

If you need after hours emergency assistance, you can contact Lifeline’s 24 hour crisis line at 13 11 14.

**‘Will I benefit from the study?’**

This study aims to gain a greater understanding of the risk factors associated with health issues and how health behaviours, health information, and psychological wellbeing contribute to quality of life across both healthy participants and clinical populations. You may find answering the questions interesting, but participating in the study will not directly benefit you.

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

Participation in this study will not cost you anything, and you will not be paid for your participation.

**‘What will happen to information about me?’**

By clicking on the ‘I agree’ button you consent to the research team collecting and using information from the questionnaire you complete for the research study. Your identity will not be collected and your responses will be collected anonymously.

This project will use an external site to create, collect and analyse your anonymous data. If you agree to participate in this survey, the responses you provide to the questionnaire will be stored on a host sever. No personal information will be collected in the questionnaire. Data will be stored on the University of New South Wales server, which is secure and password protected.

We will keep your data for a minimum of 15 years and 5 years after the final publication arising from this research. After this time, all data will be destroyed by complete deletion of the file from the computers and networks on which they are stored.

**‘What happens with the results?’**

It is anticipated that the results of this research study will be published and /or presented in peer-reviewed journals and at conferences or other professional forums for the promotion of knowledge in the health services. No identifiable data will be presented, and only average results presented. That is, the results of everyone who completes the survey will be presented together so that no single person or their responses will be identifiable. After the study is finished, a lay summary of the study findings will be available to you, via the Behavioural Sciences Unit website <http://www.behaviouralsciencesunit.org/>

**‘Do I have to sign a separate consent form?’**

No. By clicking on the ‘I agree’ button you are providing consent for your information to be included in the above named research study. Submitting your complete questionnaire is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire. Once you have submitted it, your responses cannot be withdrawn because they are anonymous and therefore we will not be able to tell which answers were yours.

**‘Who should I contact if I have concerns about the conduct of this study?’**

This study has been approved by the UNSW Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the UNSW Human Research Ethics Coordinator (phone +61 2 9385 6222, email [humanethics@unsw.edu.au](mailto:humanethics@unsw.edu.au).) Please quote the study reference number: [HC15773].

## Consent Form

### Declaration by the participants

- I have read the participants information statement;
- I understand the purpose, study tasks and risks of the research described in the project;
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the project and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I can download a copy of this consent form from [INSERT web link/web address]

**By clicking on the “next” button I agree and consent to participate in this study**

**Next**