# Online Consent Form

This survey is part of a research study conducted by Clara Wang and Chinmay Kulkarni at Carnegie Mellon University.

**Purpose**
We hope that this research will determine ways to better distribute information about educational support resources to childhood cancer survivors as well as to understand the online education resources that are most needed. The purpose of the study is (1) to determine the sources of information the childhood cancer survivors and their family find most useful, and use most often, and (2) to determine the types of educational resources childhood cancer survivors diagnosed in middle and high school and their siblings find most beneficial.

**Procedures**
If your child participates, he or she will take a brief online survey (between 2 and 8 minutes). The surveys will be emailed to participants (only if they are above age 18) or their parents or legal guardians first if they are minors. A two-week window will be given for participants to complete the questionnaire through Survey Monkey. The questions are focused on information seeking habits and education research, and are in the form of short answer or multiple-choice questions.

**Participant Requirements**
Participants in the study must be childhood cancer survivors over the age of 10 years who were diagnosed between middle and high school (6-12$^{th}$ grade) and no more than 10 years post treatment, OR their siblings who must have also been between middle and high school (6-12$^{th}$ grade) when their siblings were diagnosed.

**Risks**
The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life. There is a possibility of memory recall of unpleasant times or periods of their life. They can stop participating in the survey at any time if they wish. Additionally, there is a minor risk of a breach of confidentiality by participating. The researchers conducting the study do their utmost to secure all responses and to keep them confidential. This is done by assigning a number to responses instead of saving them by name.

**Benefits**
There may be no personal benefit from your participation in the study, but the knowledge received may be of value to humanity.

**Compensation & Costs**
There is no compensation for participation in this study
There will be no cost to you if you participate in this study.

**Future Use of Information and/or Bio-Specimens**

In the future, once we have removed all identifiable information from the survey, we may use the data for our future research studies, or we may distribute the data to other investigators for their research studies. We would do this without getting additional informed consent from you. Sharing of data with other researchers will only be done in such a manner that you will not be identified.

**Confidentiality**
By participating in the study, you understand and agree that Carnegie Mellon may be required to disclose your consent form, data and other personally identifiable information as required by law, regulation, subpoena or court order. Otherwise, confidentiality will be maintained in the following manner:

The data and consent form will be kept separate. Research data will be stored in a secure location on Carnegie Mellon property. By participating, you understand and agree that your data and information gathered during this study may be used by Carnegie Mellon and published and/or disclosed by Carnegie Mellon to others outside of Carnegie Mellon. However, names, contact information (like email addresses) and other direct personal identifiers will not be mentioned in any such publication or dissemination of the research data and/or results by Carnegie Mellon. Note that per regulation all research data must be kept for a minimum of 3 years.

The researchers will be receiving data through a third-party online survey service, SurveyMonkey. Participant names will not be connected to research data. ONCE TRANSFERRED FROM SURVEY MONKEY, all collected data will be stored in password protected locations that can only be accessed by authorized researchers. All efforts will be made to protect the privacy of participants.

**Rights**
Your participation is voluntary. You are free to stop participation at any point. Refusal to participate or withdrawal of consent or discontinued participation in the study will not result in any penalty or loss of benefits or rights to which you might otherwise be entitled. The Principal Investigator may at his/her discretion remove you from the study for any of a number of reasons. In such an event, you will not suffer any penalty or loss of benefits or rights which you might otherwise be entitled.

**Right to Ask Questions & Contact Information**
If you have any questions about this study, you should feel free to ask them by contacting the Principal Investigator, Clara Wang: claraw@andrew.cmu.edu or her Faculty Advisor, Chinmay Kulkarni: chinmayk@andrew.cmu.edu

If you have questions pertaining to your rights as a research participant; or to report concerns to this study, you should contact the Office of Research Integrity and Compliance at Carnegie Mellon University. **Email: irb-review@andrew.cmu.edu** . Phone: 412-268-1901 or 412-268-5460.

**Voluntary Participation**

Your participation in this research is voluntary. He or she may discontinue participation at any time during the research activity. You may print a copy of this consent form for your records.

I am age 18 or older. ☐ Yes ☐ No
I have read and understand the information above. ☐ Yes ☐ No