

Title: Predicting Childhood Cancer Survivors Transition Readiness &  
Transfer Outcomes (SURV Transfer Outcomes)

Date: 07/11/2023

NCT#: NCT04257058

**Emory University**  
**Online Consent and HIPAA Authorization Script/Information Sheet For a Research Study**  
**Exit Interviews to Assess Impact of Material on Health Beliefs (Study Aim 4)**

**Study Title:** Predicting Childhood Cancer Survivors' Transition Readiness & Transfer Outcomes (SURV Transfer Outcomes)

**IRB #:** 91839

**Principal Investigator:** Jordan Marchak, PhD, ABPP

**Funding Source:** Emory + CHOA Pediatric Research Alliance Grant, & National Cancer Institute

**Introduction and Study Overview**

Thank you for your interest in our Adolescent and Young Adult Survivor research study. We would like to tell you everything you need to think about before you decide whether or not to join the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.

- 1) The purpose of this study is to find out about survivors' knowledge and readiness to make the transfer to adult survivor care. It is called a behavioral clinical trial because we are seeking to find out if educational material influences survivors' ideas about healthcare.
- 2) The study is funded by an Emory and CHOA Pediatric Research Alliance Grant and the National Cancer Institute.
- 3) The questionnaires for the study will take about 15-30 minutes to complete.
- 4) If you want to join, I will ask you for your email address and your consent to send you online surveys. These surveys will ask questions about your health, emotional well-being, and transferring to adult doctors. Immediately after the first survey, we will ask you to review images and videos and to share your opinions about the media with us. Two weeks after you have completed the survey and reviewed the media, we will send you a second online survey about those materials.
- 5) You may also be invited to participate in a personal interview at the completion of the study. If you choose to participate in the personal interview, that will take about 30 minutes to an hour. If you want to take part in the interview, you will talk to a member of the study team via an online system called Zoom. We will record the conversation so that we can look back at your answers.
- 6) The possible risks of this study are minimal and include potential for loss of confidentiality of study data, including participant survey and interview responses. However, we have taken measures to secure participant information and the confidentiality of private health information (PHI) that you share with us will be kept to the highest level.
- 7) This study is not intended to benefit you directly, but we hope this research will benefit people in the future.
- 8) Once you finish each survey, we will email you a \$25 gift card to thank you for your time. If you are asked and decide to complete a study exit interview, we will email you another \$25 gift card to thank you. If you would prefer to donate your gift cards, we will give you the option to donate them toward meal tickets for Aflac patient families in need.
- 9) Your privacy is very important to us.
- 10) Your health information that identifies you is your "protected health information" (PHI).
- 11) The PHI collected during this study includes medical record information related to your childhood cancer diagnosis and treatment.
- 12) To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act (HIPAA).
- 13) The following persons or groups may use and /or disclose your PHI for this study:
  - The Principal Investigator and the research staff
  - National Cancer Institute/Emory and CHOA Pediatric Research Alliance, who funds this research, and people or companies they use to carry out the study

- Emory offices who are part of the Human Research Participant Protection Program, and those who are involved in research-related administration and billing
- Other researchers and centers that are a part of this study
- Any government agencies who regulate the research
- Possible future researchers
- Office of Human Research Protections

- 14) We will disclose your PHI when required to do so by law in the case of reporting child abuse or elder abuse, in addition to subpoenas or court orders.
- 15) You may revoke your authorization at any time by calling the Principal Investigator, Jordan Gilleland Marchak, PhD, at [REDACTED].
- 16) If identifiers (like your name, address, and telephone number) are removed from your PHI, then the remaining information will not be subject to the Privacy Rules. This means that the information may be used or disclosed with other people or organizations, and/or for other purposes.
- 17) We do not intend to share your PHI with other groups who do not have to follow the Privacy Rule, but if we did, then they could use or disclose your PHI to others without your authorization. Let me know if you have questions about this.
- 18) This research study is voluntary; you do not have to participate or give your authorization if you do not want to.
- 19) We will put a copy of this informed consent form for the research study into any medical record that you may have with Emory Healthcare facilities.
- 20) Your authorization will not expire because your PHI will need to be kept indefinitely for research purposes.

### **Contact Information**

If you have questions about this study, your part in it, or if you have questions, or concerns about the research you may contact the following:

The study PI, Jordan Gilleland Marchak, PhD : [REDACTED]

If you have questions about your rights at research participant, complaints about the research or an issue you rather discuss with someone outside the research team, contact the Emory Institutional Review Board at [REDACTED]

### **Consent**

If you would like to take part in the study, please click the "Yes" button below.

RADIO BUTTON:      Yes, I agree to take part (branch to questionnaire)  
                             No, I do not want to take part (branch to a thank you screen)

DATE FIELD (TODAY)