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City of Hope

INFORMATION SHEET FOR PARTICIPATION IN QUALITY IMPROVEMENT ACTIVITIES

Substudy under the primary study: "Leveraging digital health solutions to reduce learning and functional disparities in children with cancer"
IRB Protocol Number: *22057*

I. **PURPOSE OF THIS QUALITY IMPROVEMENT (QI) STUDY**: You have been invited to participate in a quality improvement study because you previously participated in our HIP-eHealth intervention program which provided parents of childhood cancer survivors with tools to support their child's learning and school progress. While we previously obtained helpful input from parents as they went through the program, we now wish to solicit input about the long-term impacts, if any, from families who completed the program at least 3 months ago. We wish to learn what happens in the months after they end the program, particularly about ongoing and/or new practices, barriers, or resources towards their child's school progress. We also seek to gather information about the childrens' past perspectives about the program and their current attitudes and practices toward schoolwork. The information we learn by doing this subtudy may guide changes to improve the intervention program and/or to sustain positive impacts long after families roll off the program. The main risks associated with the study include potentially feeling uncomfortable with responding to certain questions. If you don't want to answer a question, you may skip it or end the interview/survey at any time without penalty. If you agree to take part in this study, you will be asked to complete an interview or an online survey.

About 30 parent/child dyads (60 people) will participate in this study.

II. **BACKGROUND**: Parents' feedback from our ongoing program has been overwhelmingly positive. However, both this feedback and our team's observations have revealed that families engaged in the intervention program in different ways and at different levels, often depending on the family's life circumstances. Particularly, we have found that families required varied number of one-on-one meetings with our team to facilitate the childrens' consistent academic practice.

III. **WHAT WILL BE DONE**: We will interview parents/caregivers to ask about their pro-learning parenting activities and their child's academic efficacy, practices, barriers, and progress in the months after their family ended the study intervention. The interview will take approximately 30-60 minutes to complete, depending on the parent's time availability and preferences. We will also interview children, with a parent/caregiver present, about the positive and negative aspects

of their program participation, as well as their current thoughts and feelings about learning and academic progress. The interview may range from approximately 20-45 minutes depending on the child's age and ability to share their thoughts. Interviews will be audio-recorded and transcribed verbatim and will be conducted via HIPAA-compliant Teams platform.

If an interview is not feasible, alternatively, participants may complete self-administered surveys via REDCap. For children, parents/caregivers or research staff may help guide the child through the survey, but responses should be their own.

Examples questions for parents are: "*Since the program ended, how has your child been doing at school — improved, stayed the same, or worse?*", "*When you reflect back, how did participation in the program help your child with learning and academic skills, if at all?*", and "*When the program ended, did you feel ready to continue on your own? In what ways?*".

Example questions for children are: "*If a friend were having trouble with schoolwork, would you show them something you learned from your meetings with [insert study coach(es)]? What would it be?*", "*What do you do if your schoolwork feels really hard? Is there anything you do to make it easier?*", and "*Did being in the program help you do better, worse, or the same with schoolwork?*".

The interviewer will use only first names during the course of the recorded interview. Parent/caregivers and children will be assigned a code so that information from the interview or survey will be kept de-identified and will not be attached to you or your child's name or other identifying information. A password-protected electronic database on a secure server that can be accessed only by the research team will contain a link between your and your child's identifying information and the code. Interview recordings and survey responses will be located in secure databases which only key study personnel will have access to.

After completing the interview/survey, parents will be given $150 in Target gift cards and children will be given $50 in Target gift cards for their participation.

Your active participation in this study is expected to last the time it takes to complete the interview or the survey. A copy of this consent information sheet that is being reviewed with you will be provided via email.

IV. **POSSIBLE BENEFITS**: There is no guarantee that you or your child will receive any benefits from this. However, other parents/caregivers and children in the future may benefit from the information gained from your and your child's participation.

V. **POSSIBLE RISKS**: The risks and discomforts of this study are a possible breach of confidentiality and possibly becoming tired from the amount of time needed to complete the interview or survey.

Risks associated with Breach of Confidentiality:
There is a small risk that people who are not connected with this study will learn your identity or your personal information.

VI. **ALTERNATIVES TO PARTICIPATION**: Your alternative is to choose not to participate in this study. Choosing not to participate will not interfere with any future treatment at or any relationship with City of Hope.

VII. **CONFIDENTIALITY OF INFORMATION**
The research data collected will be anonymous and results will be aggregated for reporting purposes. Any data collected will be used solely for the purpose of the study. Every effort will be made to keep any information about you confidential. However, it is impossible to guarantee that information about you will not be mistakenly released. If, despite our best efforts, identifying information about you is released, it could negatively impact you or your family members. This risk is small.

By participating in the interview or survey, however, you allow the researchers to make your and your child's information available to the City of Hope research team, City of Hope Institutional Review Board (IRB) Office, the Cancer Protocol Review and Monitoring Committee (CPRMC), the Office of Human Research Protections (OHRP), the National Cancer Institute (NCI), the National Institutes of Health, and other regulatory agencies as required by law. If information learned from this study is published, you and your child will not be identified by name.

VIII. **OFFER TO ANSWER QUESTIONS**: The principal investigator, Dr. Sunita Patel, has offered to answer any and all questions regarding your and your child's participation in this research study. If you have any further questions, you can contact Dr. Patel at (626) 256-HOPE (4673) ext. 86062 or at spatel@coh.org.

X. **COST TO THE PARTICIPANT FOR PARTICIPATION**: Neither you, your child, nor your or your child's insurance carrier will be charged for your or your child's participation in this study.

XI. **VOLUNTARY PARTICIPATION WITH RIGHT OF REFUSAL**: You have been informed that you and your child's participation in this quality improvement study is voluntary. You are free to withdraw your consent for your and your child's participation in this study without any loss of benefits, penalty, or interference with any future treatment at, or any relationship with, City of Hope.

XII. **IRB REVIEW AND IMPARTIAL THIRD PARTY**: A representative of that Board, from the Office of Human Research Subjects Protection, is available to discuss the review process or your rights as a subject. The telephone number of the Office of Human Research Subjects Protection is (626) 256-HOPE (4673) ext. 62700.

Confirmation of Consent:

By completing and submitting the interview or survey, you are consenting to have the collected information used as part of this study.