

## **Consent to Participate in a Research Study Interview for Caregiver of a Child Patient**

**Title of study:**

**Principal investigator:**

**Contact phone number:** *(Include dialing code)*

**Contact email address:** *(Consider creating one specifically for the study)*

**Contact address:** *(Include zip code)*

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### **Introduction**

We are asking you to take part in a research study. To decide if you want to be part of this study or not, we will tell you about the study. We will tell you about the risks and benefits, so you can make an informed decision. This consent form describes the study.

Please read this document. You can ask any questions before agreeing to participate.

This study will investigate *[give brief description of what the study is looking to investigate - being sure to try and avoid technical / scientific language wherever possible]*.

### **What will happen in the study?**

If you decide to take part in this study, we will ask you to *[provide brief description of what the study will entail]*.

Next, we will *[include any information on any potential next steps]*.

*[Include information on the level of confidentiality they can expect.]*

### **Are there benefits to taking part in the study?**

Depending on the answer you may want to include:

There is no direct benefit to you for attendance in this study. You will help researchers understand *[include information on what the researchers are looking to get from the research]*.

## **What are the risks and possible discomforts from being in this research study?**

*[Include risks and discomforts here.]*

If you are conducting surveys / interviews:

You may feel uncomfortable answering questions in the survey or have some concerns about your privacy. We will take every precaution to maintain privacy of your data. To maintain privacy, we will destroy the audio recordings right after we transcribe them. We will store all study documents with your name and other information that identifies you removed. We will replace them with a code in these documents. We will adhere to all data privacy regulations.

## **Will I get paid for being in this study?**

You and your child will receive *[detail any gifts or financial rewards that they will receive for taking part]* after you *[detail what they have to do to be entitled to the reward]*. We will *[detail how they will receive any such reward]*.

## **What are my rights as a participant?**

Your participation is voluntary. You may choose not to take part. You can leave the study at any time without penalty.

## **What about confidentiality?**

We will collect information about you to conduct this study. We will collect *[include details on what information you will collect i.e. name, email address and phone number]*. The information we collect we'll only use for the purposes of this research as described in this consent form. Your information is stored securely with access and password control. Only the research team will have access to your information. If you do not want to allow us to use your information, you can choose not to take part in the study.

We try to keep your personal information private and confidential. However, we cannot guarantee absolute confidentiality.

There are a few times we may need to give out information that identifies you. If required by law, we may need to disclose your personal information. It may be disclosed to others as described in this section.

The following people will have access to your information if it is needed to conduct this research:

- Members of the study team (the principal investigator, interviewers, research analysts and study managers)
- People who oversee or evaluate the research at the Institutional Review Board.
- This is a group to help protect your rights as a research participant.

We may present information from this study or publish it in scientific meetings or journals. In such cases, we will not use your name.

### **How can I withdraw from the study?**

Participating in this research study is voluntary. You can choose to join or not. If you agree to participate in the study, you can withdraw at any time in the process. You can withdraw in the middle of the interview by letting the interviewer know you don't wish to continue. If you wish to withdraw from this study, please email us at [*study email address*], call us at [*study contact phone number*], or say so during the interview.

If you withdraw from the study, we may still use the information we have collected until that point. We will not collect any new information about you after you withdraw.

### **Who do I call if I have questions or problems?**

If you have questions about the study, contact [*name of Study Manager*] at [*study contact phone number*]. You can also email us at [*study email address*].

If you have questions about your rights as a research participant, you may contact [*provide details of IRB company if you are using one*].

We will give you a copy of this form.

**Signature**

- ✓ I have read the information provided above.
- ✓ I voluntarily agree to take part in this study.
- ✓ I agree that I can be recorded during the study interview according to the description above. I understand that I cannot participate if I decline to be audio recorded.

\_\_\_\_\_  
Signature of research subject

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of research subject

## **APPENDIX 1: Parental permission and affidavit**

### **Why do we need your parental permission in this study?**

We need your permission to have your child participate as well. The same information about the study applies to your child's participation. Please read this consent document before you decide to give your permission.

### **What will happen with your child in this study?**

The study researcher will: *[Provide brief description of what the study will entail].*

### **What are the risks and possible discomforts from permitting your child to participate in this research study?**

*[Include risks and discomforts here.]*

### **What are your child's rights as a participant?**

Your child's participation is voluntary. Please read this letter to your child (if age-appropriate) and inform your child that participation is voluntary. At the time of the study, the interviewer will once again remind your child of this.

### **Termination of participation**

If at any point during the study you or your child wishes to terminate the session, we will do so.

## Signature

- ✓ I hereby declare that I am a lawful parent or guardian of [*name of participating child*], a minor [*age of participating child*] years of age.
- ✓ I permit his/her participation in a research study described above.
- ✓ I agree that my child can be [*study activity*] according to the study description above.

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Signature of parent or guardian

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Date

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Printed Name of parent or guardian