

Parent Information and Consent Form - Online Survey



Cancer Pain Assessment and Management in Children: Using Social Media to Bridge the Gap

Researchers:

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Introduction

You are being invited to take part in the research study named above. If you are a parent or caregiver who has a child (aged 0 to 18 years) who has been diagnosed with cancer, is currently in remission, or is a cancer survivor, then you are eligible to complete this online survey. The lead researcher on this study is Dr. Christine Chambers, a Professor at Dalhousie University and the IWK Health Centre. This form provides information about the study. It is important that you understand the purpose of the study, how it may affect you, the risks and benefits associated with the study and what you will be asked to do before you decide if you will participate. The purpose of this Information Form is to help you decide if it is in your best interest to take part in this study. You do not have to take part in this study. Taking part is entirely voluntary (up to you). Informed consent starts with the initial contact about the study and continues until the end of the study. You may decide not to take part or you may withdraw from the study at any time. If you have any questions that this form does not answer, a member of the IWK Health Centre research team will be happy to give you further information.

Why are the researchers doing the study?

The overall goal of this study is to increase parents' awareness and use of evidence-based strategies for controlling children's cancer pain via a partnership linking internationally recognized researchers with an established online media forum, the Cancer Knowledge Network (CKN). We want to learn more about parents' knowledge and experiences with their children's

cancer pain and whether these change after the “Making Cancer Less Painful for Kids” campaign.

How will the researchers do the study?

Parents or caregivers who have a child (aged 0 to 18 years) with cancer currently in treatment, remission or who is a survivor, are eligible to complete an online survey developed by the research team but hosted on the Cancer Knowledge Network website.

What will I be asked to do?

You will be asked to answer a survey (it will only take about 10-15 minutes) about your child with cancer. We want to learn more about parents’ knowledge and experiences with their children’s cancer pain and whether these change after the “Making Cancer Less Painful for Kids” campaign. We will ask you questions about any pain that your child has experienced (from disease, medical procedures, and treatments), how you usually deal with it, and your thoughts on pain more generally. You will also be asked a few demographic questions (e.g., age, education, etc.). All of your answers on this survey are totally anonymous.

At the end of this survey, if you provide your contact information (which will not be linked to your survey answers) you will be entered into a draw for one of three Visa gift cards worth \$250. Prizes will be randomly drawn following the close of the online survey, approximately one month after the survey opened, and winners will be contacted by the research team.

Also at the end of the survey, you will be asked if you are willing to provide your contact information so that the research team can contact you for further research. This is so we can invite you to participate in other research opportunities on children's cancer pain, as well as to participate in a similar survey 12 months from now at the end of the year-long #KidsCancerPain campaign. Parents and caregivers who complete both surveys can enter another draw for one of three Visa gift cards worth \$250.

Potential harms and burdens

Some people may find some of the questions in the survey distressing. We will be carefully examining the responses but will be unable to address specific concerns raised for you or your child. Please visit your health care professional to discuss any concerns you may have about your child or your child’s care. Although taking part may not benefit you or your child directly, the results may benefit other families by helping researchers to understand more about cancer pain and the impact of the “Making Cancer Less Painful for Kids” campaign.

What alternatives to participation do I have?

Before deciding to enrol in this study, you should know that you do not have to take part.

Can I withdraw from the study?

Taking part in this study is entirely voluntary (your choice). The results are completely anonymous and so you cannot withdraw once your survey is submitted. You can, however, decide to end the survey at any point (your partially completed survey data may be still be used).

Costs and reimbursements

There are no costs associated with participating. At the end of survey you may choose to enter a draw to win **one of three Visa gift card valued \$250**. Those who complete the first survey, and choose to complete the 2nd survey in 12 months' time will be entered into a draw **for one of three Visa gift card valued \$250**. Winners will be randomly chosen and contacted directly by CKN. Please note your contact information will not be linked to your anonymous survey responses.

Are there any conflicts of interest?

None.

What about possible profit from commercialization of the study results?

None.

How will my privacy be protected? What are my research rights?

The survey has been designed so that your responses are completely anonymous. All electronic study records will be kept by CKN. The survey will be conducted using SurveyMonkey software, with servers based in the United States. While all possible measures will be taken to protect the privacy of your information, protection against access under US law, cannot be guaranteed. Researchers at the IWK Health Centre's will only receive anonymized data (with your name removed) from CKN which will be kept secure servers **at the IWK Health Centre** in Halifax, NS, Canada for a minimum of 5 years following publication. Only research staff and the IWK Health Centre's Research Ethics Board will be able to access study information.

Your completion of the survey will serve as your consent to participate. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. If you have any questions at any time during or after the study about the research in general you may contact the IWK Health Centre's Research Office at (902) 470-8765, Monday-Friday, 9am-5pm AST.

How will I be informed of study results? If you wish to receive a summary of the results, they will be posted on our website www.pediatric-pain.ca and social media (e.g., Facebook: <https://www.facebook.com/CentreforPediatricPainResearch>) once the study is completed.

What if I have questions or problems? Comments, questions, or concerns can be directed to Dr. Christine Chambers at Christine.Chambers@dal.ca or Dr. Jennifer Parker (Research Associate/Project Coordinator) at JenniferA.Parker@iwk.nshealth.ca