



FAMILY INFORMATION FORM

Study Title: Supporting Healthcare Providers Efforts to Provide High-Quality Family-Centered Care to Children with ASD: A Pilot Trial of a Novel Online Theory-Driven Intervention

Descriptive Title: Supporting Healthcare Providers Efforts to Provide Care to Children with Autism Spectrum Disorder

Researchers:

Stephanie Snow, BA, Doctoral Student in Clinical Psychology, Principal Investigator

Jill Chorney, PhD, R. Psych, Clinical Psychologist, Supervising Investigator

Isabel Smith, PhD, R. Psych, Clinical Psychologist, Co-investigator

Funding:

Dalhousie University Department of Anesthesia.

Introduction:

You and your child are being invited to take part in a research study. This form gives you information about the study. Before you decide if you want to take part, it is important that you understand why we are doing this study. Whether or not you decide to take part in the study is entirely your choice (i.e., voluntary). *Informed consent* starts with the initial contact about the study and continues until the end of the study. One of the study researchers will be available to answer any questions you have. You may decide not to take part or you may withdraw from the study at any time. *This will not affect the care you or your child receives from the IWK Health Centre in any way.* You do not have to take part in this study.

Why are the researchers doing the study?

We are testing an online educational program designed to help healthcare providers learn how to support children with autism spectrum disorder (ASD) and their parents on the day of surgery. To see whether this program benefits children and families, we are gathering information on families' views on their children's surgical experience.

How will the researchers do the study?

All healthcare providers working at the IWK Day Surgery unit will be invited to complete the online program. We will invite about 25 families with children with ASD who undergo outpatient surgery at the IWK to participate before and after the healthcare providers complete the program (50 families total). Afterward, we will look at the results to help us see if providing this program to healthcare providers made a difference to families' experiences.

What will I be asked to do?

If you received this information form via email it means that you provided your contact information to your child's healthcare providers to express your interest in the study. If you are no longer interested, you can call Stephanie Snow at 902-479-6448 to opt out of the study. Otherwise, we will call you within about 48 hours of your child's surgery. After we have confirmed that you understand the information in this form and obtain your verbal consent we will ask our questions over the phone. You will be asked to provide some basic information about you and your child, like how old you are, when/where your child received his/her ASD diagnosis, and what your child's previous healthcare experiences have been like. We will then ask questions related to your views on many aspects of your child's surgical experience and the care they received. You will be asked to rate items using options like 'strongly disagree', 'disagree', 'neither agree or disagree', 'agree', or 'strongly agree'. If you think that a question does not apply to you or your child, you can say so. We will ask you some open-ended questions and invite you to make other comments. Completing the phone survey with the researcher should take about 20-30 minutes. Two weeks later, we will email you a brief optional survey asking more about your child's behaviour after their surgery. This optional survey is to be completed online and it should not take longer than 5 minutes.

Who can participate?

All English-speaking families with a child with a known ASD who is undergoing outpatient surgery at the IWK will be invited to participate in our study. Only English-speaking families will be recruited because the survey questions are only available in English.

What are the burdens, harms, and potential harms?

We do not believe there are risks or harms for you in taking part in this study. There is a risk that your personal information could unintentionally be shared, but we take all measures available to us to protect your privacy. If you do become upset over the questions asked in this study, please call 902-470-6448 and we will arrange for you to speak to Dr. Jill Chorney or Dr. Isabel Smith, who are both registered psychologists and investigators of this study. If you prefer to speak with someone not associated with this study, you will be given a list of private practitioners that you could contact.

If you have specific feedback or concerns related to your child's surgical care you would like to make sure that the IWK receives, we encourage you to call the Patient & Family Feedback line at 902-470-8103.

What are the possible benefits?

There are no direct benefits for you or your child if you take part in this study. However, the information gained from this study may help us improve surgical care in the future.

What alternatives to participation do I have?

You and your child do not have to participate in this study. Not participating will not affect your family's care from the Day Surgery team or other services at the IWK Health Centre.

Can I withdraw from the study?

You may decide to withdraw from the study at any time. Withdrawing from the study will not affect the care your child receives from the IWK Health Centre. If the study is changed in any way that could affect your decision to continue to take part, you will be told about the changes and you may be asked to sign a new consent and authorization form. Should you decide to withdraw from the study, you can request that all data collected up to that point is discarded and not used in the study.

Will the study cost me anything and, if so, how will I be reimbursed?

This study will not cost you anything. It will, however, take a brief period of your time to complete the survey with the researcher. To thank you for your time we will enter you in a draw for an iPad, if interested.

Are there any conflicts of interest?

The investigators have no conflicts of interest. Dr. Smith may have been involved in your child's clinical care in the past.

How will my privacy be protected?

You and your child will not be named in any reports or publications based on this research. Only an ID Number will be used on the questionnaire and form you complete. All information collected from you will be stored in a locked cabinet at the Centre for Pediatric Pain Research, IWK Health Centre. All information we collect will be kept until 5 years after the results have been published in presentations, posters or journals. Only staff immediately involved in the research will have access to the information you give us. All studies conducted at the IWK Health

Centre may be audited by the IWK Health Centre's Research Ethics Board. In case of an audit, your privacy will continue to be protected to the maximum extent allowable by the law.

What if I have study questions or problems?

If you have any questions about this study, please feel free to contact Stephanie Snow, the Principal Investigator, at 902-470-6448.

What are my research rights?

When we call you the first thing we will do is ask for your verbal consent. Your verbal consent indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator(s), sponsors, or involved institution(s) from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing the health care you are entitled to receive.

If you have any questions at any time during or after the study about research in general, you may contact the Research Office of the IWK Health Centre at 902-470-8765, Monday to Friday between 8 am to 4 pm.