

UNIVERSITY OF CALIFORNIA LOS ANGELES

STUDY INFORMATION SHEET

Emotion Regulation, Health, and Development in Children with OCD

INTRODUCTION

Emily Ricketts, Ph.D., from the Department of Psychiatry at the University of California, Los Angeles (UCLA) is conducting a research study. You were selected as a possible participant in this study because you are either a child between the ages of 10-17 years who has been diagnosed with Obsessive-Compulsive Disorder (OCD) or their parent. You and your child's participation in this research survey is voluntary.

WHAT SHOULD I KNOW ABOUT A RESEARCH STUDY?

- Whether or not you and your child take part is up to you and your child.
- You and your child can choose not to take part.
- You and your child can agree to take part and later change your minds.
- You or your child's decision will not be held against either of you.

WHY IS THIS RESEARCH BEING DONE?

The goal of the survey is to examine emotion regulation, health, and developmental factors (e.g., sleep-wake profiles, sleep disturbance, sleep patterns, puberty, family accommodation) in children with OCD.

HOW LONG WILL THE RESEARCH LAST AND WHAT WILL I NEED TO DO?

Participation will last approximately 45 minutes

If you and your child volunteer to participate in this study, the researcher will ask you and your child to do the following:

- Complete an internet survey lasting approximately 45 minutes (25 minutes for parent questionnaires and 20 minutes for child questionnaires) including questions about your child and families' demographic and medical/psychiatric history, followed by questions regarding your child's obsessive-compulsive symptom severity, associated impairment, family accommodation, internalizing and externalizing symptoms, anxiety sensitivity, sleep-wake profiles (i.e., chronotype), sleep disturbance, and sleep patterns. You will then be prompted to ask your child to complete the remaining portion of the survey in private, unless assistance is needed. Children will answer questions regarding their OCD symptoms, associated impairment, sleep-wake profiles (i.e., chronotype), sleep disturbance, sleep patterns, externalizing and internalizing symptoms, and emotion regulation.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

- It is possible that you and your child may become frustrated, bored, anxious, irritable, or embarrassed during the survey due to certain questions. However, you will both be able to take breaks if needed.
- Your IP address (or your child's) will be recorded to prevent survey retakes. However, it will not be linked with survey data.

- Your or your child's email address will be temporarily linked to your survey responses during the data collection phase (on Qualtrics only) for the purposes of quality assurance checks for study payments. However, email addresses will only be stored in Qualtrics and will be separated from data before completing data analysis.
- There is a risk of intrusion by outside agents (e.g., hacking) when performing internet-based procedures. However, Qualtrics encrypts user data and requires a username and password for user account access.

ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?

You and your child will not directly benefit from this study.

The results of this research will, however, be used to understand emotion regulation in OCD, and its associations with obsessive-compulsive symptom severity, psychiatric comorbidities, functional impairment, and medication usage. We hope that results will be able to improve treatments for OCD, including the relevant emotion regulation dimensions and developmental factors to target.

HOW WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

The researchers will do their best to make sure that you and your child's private information is kept confidential. Information about you and your child will be handled as confidentially as possible, but participating in research may involve a loss of privacy and the potential for a breach in confidentiality. Study data will be physically and electronically secured. As with any use of electronic means to store data, there is a risk of breach of data security.

USE OF PERSONAL INFORMATION THAT CAN IDENTIFY YOU:

Your or (your child's) email address and IP address will not be shared with anyone outside of the research team, will be stored separately from the survey database, and will not be linked to your data outside of Qualtrics.

HOW INFORMATION ABOUT YOU WILL BE STORED:

Data from this study will be stored in two ways, including in a database on a password-protected computer, and on Qualtrics survey-hosting website, which encrypts user data, allows for transmission of data over secure HTTPS connection and requires a username and password and special permissions for user account access.

PEOPLE AND AGENCIES THAT WILL HAVE ACCESS TO YOUR INFORMATION:

The research team and authorized UCLA personnel may have access to study data and records to monitor the study. Research records provided to authorized, non-UCLA personnel will not contain identifiable information about you or your child. Publications and/or presentations that result from this study will not identify you or your child by name.

HOW LONG INFORMATION FROM THE STUDY WILL BE KEPT:

IP addresses will be separately stored for three years following the survey. The de-identified database will be kept indefinitely for future research. Email addresses will be delinked from the data immediately after data collection concludes.

USE OF DATA FOR FUTURE RESEARCH

You and your child's data, including de-identified data may be kept for use in future research.

WILL I BE PAID FOR PARTICIPATING?

You and your child will receive a \$10 Amazon e-gift card upon survey completion. At the end of the survey, you and your child will be provided with an email address that you can email to receive your \$10 Amazon e-gift card. Survey completion and successful passing of quality assurance checks within the survey are required to receive study compensation. “

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

- If you or your child have any questions, comments or concerns about the research, you can talk to one of the researchers. Please contact: Emily Ricketts, Ph.D. at ERicketts@mednet.ucla.edu or Maya Tooker, B.S. at mtooker@mednet.ucla.edu.
- **UCLA Office of the Human Research Protection Program (OHRPP):**
If you or your child have questions about your rights while taking part in this study, or have concerns or suggestions and want to talk to someone other than the researchers about the study, please call the OHRPP at (310) 825-7122, email at participants@research.ucla.edu, or write to:

UCLA Office of the Human Research Protection Program
11000 Kinross Avenue, Suite 211, Box 951694
Los Angeles, CA 90095-1694

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

- You and your child can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time.
- Whatever decision you and your child make, there will be no penalty to you or your child, and no loss of benefits to which you were otherwise entitled.
- You and your child may refuse to answer any questions that you or your child do not want to answer and still remain in the study.