

Assessment of Pediatric Pain: Enhancing the Understanding of Initial Presentation, Treatment Responsiveness, and Psychosocial Factors in Pediatric Pain Patients in Outpatient and Intensive Outpatient Programs

1. What will happen to me in this study?

You are invited to participate in a research study to better understand pain conditions and psychosocial outcomes related to pediatric pain. Our team wants to understand how pain affects what you think, how you feel, and where you do things in your day-to-day life. We hope to improve how we evaluate (ask about) and treat (help) pain by learning from you and your family. Your parent already received an email before this first visit to our Pain Clinic, and you both were asked to answer questions online. Thank you for doing that!

If you agree to be part of this study, we will use your responses to improve how we help kids and families like yours in the future. You will also be asked to answer some of the same questions in 3, 6, 9, 12, and 24 months, and if you receive ongoing outpatient care at the pain clinic, shortened surveys every two weeks or more. At any time you have the right to refuse to answer particular questions. This study is not an experiment, so you will not be asked to do anything but answer questions online. We are happy to talk to you about the questions if you wish to.

TIME INVOLVEMENT:

Pediatric Pain Management Clinic/Outpatient Clinic (PPMC): if you choose to follow-up with the Pediatric Pain Management Clinic after this first visit, and agree to participate in this research, you will be asked to complete similar questionnaires online in three, six, nine, 12, and 24 months. Baseline questionnaires will take approximately 45 minutes, while subsequent questionnaires at follow-up will approximately 30 minutes to complete online. The shortened surveys every two weeks or more will take about 10 minutes to complete online.

2. Can anything bad happen to me?

It is up to you to decide if you want to participate. Helping with this study will not cause anything bad to happen to you. We do want you to be honest in answering the questions, and no one but us will know your answers. If you do not understand some questions, or some questions make you feel worried or sad, our team will be happy to talk to you.

3. Can anything good happen to me?

We cannot and do not guarantee or promise that you will receive benefits from this study. However, being part of our study may help you feel good about being involved in research for kids with chronic pain. If you agree to do this study, you will express how you feel about your pain, and what you do about it. We will study and share what we learned from you to help other kids with pain in the future, and can share those results with you if you would like. Your participation in this study will give us information that can then be used to help providers improve the assessments (ratings) they do, and the interventions (treatments) they offer to reduce the impact of pain on your life.

4. Do I have other choices?

Of course! Your participation in this study is *your* choice, and you can stop being in this study at any time. The other choice is not to participate, and this is okay with us. It will not affect how we take care of you at Stanford.

5. Will anyone know I am in the study?

Your participation in this study will be kept confidential (secret). No one but our pediatric research team will know that you are participating. Even your parents will not know how you answer questions, unless you want them to, or we have to tell them something to keep you healthy.

6. Who can I talk to about the study?

If you have any questions about the study or any problems with the study you can contact the Protocol Director, Dr. Samantha Huestis at (650) 736-3482. You can also call Co-Protocol Director Dr. Rashmi Bhandari, PhD, at (650) 724-5333.

If you have questions about the study but want to talk to someone else who is not a part of the study, you can call the Stanford Institutional Review Board (IRB) at (650) 723-5244 or toll free at 1-866-680-2906.

7. What if I do not want to do this?

Your participation in this study is voluntary, meaning you can choose to be in the study or not. It is 100% up to you and your parents. Even if you decide to do the study and then change your mind, that is okay. Our medical team will continue to work with you and help you if you need it.