

**Assessment of Pediatric Pain: Pediatric Rehabilitation Program****1. What will happen to me in this study?**

We are asking you to be in a research study to understand more about kids with pain and how they deal with it. Our team wants to know how pain affects what you think, how you feel, and what you do in your day-to-day life. We want to improve how we evaluate (ask about) and treat (help) kids with pain by learning from you and your family.

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 months, 1, 2, 3 years. At anytime, you have the right to refuse to answer particular questions. In this study you will answer questions on an iPad or on paper with pencil and take some pictures of things to explain your pain. We are happy to talk to you more about what you will be doing in this study.

**WHAT YOU WILL BE DOING:**

1. You and your parent will answer questions on an iPad or on paper with pencil that will take about 45 minutes on your first day in the program. We will make sure you have time in your schedule to finish the questions. You will answer these questions again when you end the program in several weeks and again in a few months.
2. You will be asked to take some pictures with your smartphone or one of our digital cameras to explain how pain has been a problem for you. You will be asked to take pictures of things to tell a story about your pain. Your pictures should not have anything that could show that it is from you, so no pictures of your face or anyone else's face, no names, no addresses, or anything that could link the pictures to you.
3. You and your parent will also answer questions on an iPad or on paper with pencil that will take about 15 minutes once a week.

**TIME INVOLVEMENT:**

Pediatric Rehabilitation Pain Program (PReP): if you agree to participate in this research, after your graduation from the rehabilitation pain program, you will answer the same questions 3, 6, 9 months, 1, 2, and 3 years after you finish the program. The first time you answer the questions it might take about 45 minutes, but the weekly questions you answer after that will only take about 15 minutes. Once you finish the program you will answer all of the questions again and that might take 30 to 45 minutes to complete online.

**2. Can anything bad happen to me?**

It is up to you to decide if you want to be part of the research study. 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, the questions that you will answer will be used to make sure we know how well the program is helping you. 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 can tell us 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 we can share those results with you if you would like. You will help to give us information that can be used to improve treatment 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 and you can just answer the questions that are part of your treatment in PReP. Being in the study 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. Anya Griffin at (650) 736-3656. You can also call Co-Protocol Director, Dr. Amanda Feinstein at (650) 736-3494.

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.