

SANTA BARBARA • SANTA CRUZ

PARENT PERMISSION FOR CHILD TO PARTICIPATE IN A RESEARCH STUDY Helping Our People End Suicide Study

Youth

Key Information

- Your child is being invited to participate in a research study. Participation in research is completely voluntary.
- The purpose of the study is to create culture-based suicide screener to be used in the Sacramento Native community.
- The study may take up two hours. Your child will be asked to complete one survey and either a one-on-one interview or a focus group interview.
- Your child will answer questions about what a culture-based suicide screener should look like and how it should be used.
- Risks and/or discomforts may include the triggering of unwanted emotions from talking about suicide and mental health. There is also a risk of breach of confidentiality.
- There is no direct benefit to you or your child. The results from the study may help prevent Native and Indigenous youth suicide.

Introduction

My name is Val Sierra. I am a graduate student at the University of California, Berkeley working with my faculty advisor, Doctor Adrian Aguilera. We invite your child, with your permission, to participate in this study. The study is called the Helping Our People End Suicide (HOPES) Study.

Before you and your child decide whether they will be part of this study, it's important for all of you to understand why we're doing the research and what's involved. Please read this form carefully. Your child will receive their own assent form. We encourage you to discuss the study with your child. If you or your child has questions about the research, feel free to ask us.

Purpose

The goal of the HOPES Study is to create a culture-based suicide screener. Our hope is to prevent suicide by connecting youth in need of extra support to health care services at places like the Sacramento Native American Health Center (SNAHC). The study aims to increase access to culturally relevant care for all Native and Indigenous youth in the Sacramento area.

This study is not part of your child's schoolwork, and it will not be graded. It will also not impact their participation in the programs at SNAHC.

Procedures

If your child decides to participate and you give permission, we will ask them to:

• Complete a demographics survey

CPHS #2021-04-14226 Page 1 of 4

First, your child will fill out a demographics survey. It will ask questions about your child's age, race, and other details. They do not have to answer questions they do not feel comfortable answering. This part will take about five (5) minutes.

• <u>Have a one-on-one interview (Possible)</u>

Some people who agree to be in the study will participate in a one-on-one interview. If your child is chosen, I will contact you to schedule a time to meet that works best for you and child. The interview will take place after school online using Zoom.

We will ask your child questions about culture, mental health, and suicide prevention. I will audiotape or record what we're saying if you give me permission. Your child does not have to answer all the questions if they do not feel comfortable sharing. I can also stop the recording or stop the interview at any time if your child wants me to. You and your child can decide a place that is convenient such as a private room at your home for the interview. The interview will take about 90 minutes or $1\frac{1}{2}$ hours.

Once I have transcribed the interview, I will share it with your child to make sure I got everything correct. All the changes they request will be made.

• Partake in a focus group interview (**Possible**)

Some people who agree to be in the study will participate in a focus group interview. If your child is chosen, I will contact you to schedule a time to meet that works best for you and your child. The focus group will take place after school online using Zoom.

We will ask your child questions about culture, mental health, and suicide prevention. I will audiotape or record what we're saying if you give me permission. Your child does not have to answer all the questions if they do not feel comfortable sharing. I can also stop the recording or stop the interview at any time if your child wants me to. The focus group will take about 90 minutes or $1\frac{1}{2}$ hours.

Once I have transcribed the focus group, I will share it with your child to make sure I got everything correct. All the changes they request will be made.

Total time: The study may take up 95 minutes or one (1) hour and 35 minutes. The survey will take about five (5) minutes. If your child is selected to have a one-on-one interview, the whole study will take about 95 minutes. If your child is selected to be part of the focus group interview, the whole study will take about 95 minutes.

Study location: All study procedures will take place online.

Benefits

There is no benefit to you or your child personally for taking part in this study. However, we hope that the results of the research will lead to the creation of a suicide screener that will help prevent suicide among Native and Indigenous young people in the Sacramento area.

Risks/Discomforts

CPHS #2021-04-14226 Page 2 of 4

- Some of the questions will talk about mental health including suicide. Your child might feel certain emotions that can make them uncomfortable or upset. If so, your child can just tell us that they wish to stop.
- Breach of Confidentiality: A possible risk for any research is that confidentiality could be compromised, that is, people outside the study might get hold of confidential study information. We will do everything we can to minimize this risk.

Below are some resources that may help your child if they need more support. Your child can use these supports anytime during the study. They include:

- Talking with a mental health and crisis support line like:
 - o National Suicide Prevention Hotline (800) 273-8255
 - o The Trevor Project (866) 488-7386
 - o Trans Lifeline (877) 565-8860
 - o Sacramento County Suicide Prevention Crisis Hotline (916) 368-3111

Confidentiality

All study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used.

To help protect confidentiality, we will give your child's study data a code number and keep it in a file with a password that only the researchers know. This will help keep your child's information private and anonymous. All data will be stored by SNAHC using the standards set by the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Personal information may be released if required by law. Authorized representatives from the following organizations may review your research data for purposes such as monitoring or managing the conduct of this study:

- Sacramento Native American Health Center, Inc.
- University of California

Sensitive/reportable research information:

We will keep all study data as confidential as possible, with the exception of certain information that we must report for legal or ethical reasons. This includes instances of child abuse, elder abuse, or intent to hurt yourself or others.

Retaining research records:

When the research is completed, SNAHC will save all study data for use in future research done by myself or others. SNAHC will retain these records indefinitely. The same measures described above will be taken to protect your child's confidentiality. Additional informed consent from you or a legally authorized representative is required for future research studies. The study data will not be distributed to other agencies for future research studies.

Compensation/Payment

Your child will receive a \$25.00 Target gift card as a thank-you for their time and effort to take part in this study. Your child will receive the gift card in an email sent to them within two weeks after the end of their part in the study.

Rights

CPHS #2021-04-14226 Page 3 of 4

Participation in research is completely voluntary. You have the right to decline to allow your child to participate or to withdraw your child at any point in this study without penalty or loss of benefits to which you are otherwise entitled. Your child has the same rights to decline to participate or withdraw from the study at any time.

Questions

You can contact us if you have questions about the study, or if you decide you do not want your child to be in the study anymore. You can talk to me or SNAHC's Community Health Department Manager at any time during the study. You can ask questions about this study at any time, now or later.

You can contact me, Val Sierra, at **(530) 488-9902** or **vqsierra@berkeley.edu**. Or you can contact Lauren Lockhart, at **(916) 341-0576 x4415** or **lauren.lockhart@snahc.org**.

If you have any questions or concerns about your rights and treatment as a research participant, you can contact UC Berkeley's Committee for the Protection of Human Subjects, at (510) 642-7461 or subjects@berkeley.edu.

CPHS #2021-04-14226 Page 4 of 4