

INFORMED CONSENT FORM FOR RESEARCH PARTICIPATION

Title of Project: Title V Maternal and Child Health (MCH) Block Grant Jurisdictional MCH Survey Instrument

Person in Charge of Study: Caitlin Oppenheimer, Senior Vice President, Public Health Department NORC at the University of Chicago

Why are you doing this Study? We are testing survey questions to learn more about mother’s and children’s health. We are doing this test in American Samoa, Federated States of Micronesia, Guam, Marshall Islands, Northern Mariana Islands, Palau, Puerto Rico, and U.S. Virgin Islands. These areas are part of the Title V MCH Block Grant program. Local MCH programs will use these questions to understand the health of mothers and children. This will help them develop services for families.

1. **Who is funding this Study?** This study is paid for by the Health Resources and Services Administration.
2. **What would I be asked to do if I am in this study?** You will be asked to answer survey questions that are read out loud to you. The questions are about your and your child’s health. For example, we will ask about your child as a baby, caring for your child, and your child’s learning. We will also ask about illnesses you or your child may have had, doctors you and your child see, household information, and other kinds of questions.
3. **Voluntary Participation:** You don’t have to be in this study. You can agree to be in the study now and change your mind later. You do not have to answer any questions you do not want to answer. Your decision to not answer questions or to stop answering questions will not change anything.
4. **Discomforts and Risks:** There are no risks in answering these survey questions beyond the risks that are in everyday life. Some of the questions about health, drug or alcohol use, or feelings are personal and might make you uncomfortable.
5. **Benefits:** There is no direct help to you for answering the survey questions, your answers may help provide better information about the health of mothers and children and the work of the Title V MCH Block grant program.
6. **How long will it take for me to participate in this study?** It will take about 40 minutes to answer the questions.
7. **Confidentiality:** The only people allowed to see your answers will be the people who work on the study and people who make sure we run the study the right way. Your name will not be on the survey with your answers. We will use a number code to track your answers, not your name.

The survey does not ask about child abuse or neglect. If we learn about child abuse or neglect that is happening now or is ongoing, we will have to report this to the proper authorities.

Your answers will be written down on paper. A copy of the survey will be sent to our offices in Chicago, Illinois using a computer. We will do our best to keep your answers private, but no one can promise that answers sent over the Internet can be kept private. As soon as your responses are sent, we will shred the paper with your answers. Any paper with your answers will be kept safe in a locked cabinet until it is shredded.

If you stop answering questions before the end of the survey, you can ask us to shred your responses.

8. **Certificate of Confidentiality:** We have asked the U.S. Department of Health and Human Services (DHHS) to give this study a legal document, called a Certificate of Confidentiality. This means that the study cannot be made to give out your answers in any court. We will only share your answers if you request it.

Studies like this one can be looked at by the United States Government. If that happens, we cannot use the Certificate of Confidentiality to keep your answers from staff doing the review.

9. **Right to Ask Questions:** Please contact Clare Davidson at [toll free number pending] or JCMH@norc.org with questions, complaints or concerns about this study. If you have any questions or concerns about your rights as a research participant, please contact the NORC Institutional Review Board Manager by toll-free phone number at (866) 309-0542.

You must be 18 years of age or older to take part in this research study.

If you agree to take part in this research study, please sign your name and write the date below.

You will be given a copy of this consent form for your records. Please keep this form for your records or future review.

Participant Signature

Date

Person Obtaining Consent

Date