FREQUENTLY ASKED QUESTIONS

Why are you doing this study?

We are doing this research study to learn about your medical history and how your family talks about health and cancer.

Who is funding this study?

This study is paid for by the Centers for Disease Control & Prevention (CDC).

How long will it take for me to participate in this study?

It will take about 20 minutes to complete the survey.

How do I know this study is real or valid?

Please contact Juan Rodriguez at the CDC at (XXX) XXX-XXXX with questions, complaints or concerns about this research.

What types of questions will you ask?

The survey will include questions about you and your health and cancer in your family. You may skip questions you do not want to answer and you can stop the survey at any time.

How much will I be paid for participation?

For this survey, you will receive \$5 cash in the mail upon completion.

Who is NORC at the University of Chicago?

NORC at the University of Chicago (NORC) is an independent research organization that is doing this study on behalf of the CDC. More information on NORC can be found at www.norc.org.

Will the information I give you be kept private?

All answers to survey questions will be kept private to the extent allowed by law. Only NORC study staff will ever see any personal information that could identify you as a participant. Information that could identify you in any way will be kept separate from answers to survey questions. We will combine your answers with answers from others participating in the study when writing summary reports or papers. Your name or other information that identifies you will never be reported.

No information that could identify you will be given to CDC. CDC staff will only have access to responses to survey questions. All identifying information will be destroyed once the study is complete.

This research is covered by a Certificate of Confidentiality from the Centers for Disease Control and Prevention. The researchers with this Certificate may <u>not</u> disclose or use information or documents that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or proceeding, or be used as evidence, for example, if there is a court subpoena, unless you have consented for this use.

Will my answers be safe online?

We will do our best to protect all the information we collect from you, but no one can guarantee complete confidentiality for data that is sent over the Internet. Information collected is encrypted at all times. Our secure servers use "HTTPS" to ensure encrypted transfer of your data between your browser and our servers. The survey link is also independently verified by Network Solutions as a secure website.

Will you ever sell my name, address, telephone number, or other information?

No. Your information is kept private, and your answers are used for research purposes only. If you have questions about your rights as a study participant, you may call 1-866-309-0542, toll-free, and leave a message asking to speak to the Head of the Institutional Review Board.

If I need to step away, can I return and complete the study online at a later time?

Yes, if you provide(d) your email address at the beginning of the survey. We will email you a personal link so that you can return to the study online and pick up where you left off.

Are there any risks to me if I decide to be in this study?

There are minimal risks to participating in this study. You may find some of the questions make you feel uncomfortable. You may skip questions you do not want to answer and you can stop the survey at any time.

Are there any benefits from being in this study?

You taking the survey will help us understand issues important to health and cancer. Findings from this study will help inform future development of tools and resources to improve health.

I'm having technical issues with the survey form.

You may call our study partner, NORC, toll free at (800) 487-4934 or email CancerSurvey@norc.org for assistance.

