University of Michigan

Consent To Be Part Of A Research Study

### Name of Study and Researchers

**Title of Project:** Calibration Survey for Michigan Genetic Hereditary Testing

**Principal Investigators from the University of Michigan:** Elena Stoffel, MD, MPH, Department of Internal Medicine, Jennifer J. Griggs, MD, MPH**,** Ken Resnicow, PhD, Health Behavior Health Education

### GENERAL Information

We’re doing a multiphase project that seeks to increase the proportion of patients in whom family history is documented, and assess for genetic risk and genetic evaluation completion. We created this survey that includes questions that may or not be used in future interviews of persons with a personal or family history of cancer. To get this information, we’d like interested participants to answer a calibration survey. We expect it to take about 20 minutes to complete the survey.

Answering this survey is completely voluntary. It’s possible that some of the questions may make you feel uncomfortable. You may answer or skip any of the questions. Choosing not to answer a survey question won’t affect the medical care you might receive at the University of Michigan Health System or other health care providers.

To keep your information confidential, your survey responses will be stored on the secured survey site. Although we keep a list of people who answered the screening survey, no one outside our study team will have access to any responses. We plan to publish what we learn from this study, but we won’t include any personal information that would reveal who answered the survey. Your identifiable private information may be stripped of identifiers and used for future research studies or distributed to another researcher for future research studies without additional informed consent.

You may benefit by participating in this survey. You may learn about the barriers in talking about cancer and genetic testing with family members. In addition, the results of this study will be used to improve access to and education about genetic counseling services to identify individuals in community who are at-risk for cancer. It’s important to identify at-risk individuals with tests that may find cancer in the body earlier in life.Depending on your experiences, you may be invited to participate in an optional follow-up interviews.

To thank you for taking part in our study, we’ll send you a $[x] gift card after you take the survey. The University of Michigan accounting department may need your name, address, payment amount, and related information for tax reporting purposes.

### AUTHORIZATION TO RELEASE PROTECTED HEALTH INFORMATION

If you were contacted through the Cancer Genetics Registry (HUM # 00043430), you have signed a consent document that has allowed us to contact, you regarding future research. Your personal health information was used to determine if you are eligible to participate in this study.

As a rule, the researchers will continue to use information about you until the study is over and will keep it secure until it is destroyed. Limited information about you may continue to be used after the study is over, for other research, education, or other activities. But use of this information would not reveal your identity.

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System’s privacy policies. For more information see <http://www.med.umich.edu/hipaa/npp.htm>. Note that once your information has been shared with others, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

### Contact Information

## To find out more about the study, to ask a question or express a concern about the study, or to talk about any problems you may have as a study subject, you may contact one of the following:

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| **Principal Investigator:** Elena Stoffel, MD, MPH  **Email:** [estoffel@med.umich.edu](mailto:estoffel@med.umich.edu)  **Phone Number:** 734-763-2532 | **Study Coordinator:** Emerson Delacroix  **Email:** emmed@med.umich.edu |

**You may also express a concern about a study by contacting the Institutional Review Board:**

University of Michigan Medical School Institutional Review Board (IRBMED)

2800 Plymouth Road

Building 520, Room 3214

Ann Arbor, MI 48109-2800  
734-763-4768

E-mail: [irbmed@umich.edu](mailto:irbmed@umich.edu)

If you are concerned about a possible violation of your privacy or concerned about a study, you may contact the University of Michigan Health System Compliance Help Line at 1-866-990-0111.

### SIGNATURES

**Research Subject:**

I understand the information printed on this form. My questions so far have been answered.

Signature of Subject: Date:

Name (Print legal name):