

## RESEARCH SUBJECT INFORMATION FORM

**TITLE:** Implementing Personal Health Records to Promote Evidence-Based Cancer Screening

**VCU IRB NO.:** HM\_\_\_\_\_

**SPONSOR:** National Cancer Institute

If any information contained in this consent form is not clear, please ask the study staff to explain any information that you do not fully understand.

### PURPOSE OF THE STUDY

The purpose of this research study is to learn how primary care doctors can best help their patients get the preventive care they need to stay healthy. The researchers have designed a website that helps patients see and understand their health information. The researchers would like to hear some patients' opinions about what kind of information they would find helpful on the website and what would keep them from using the website.

You are being asked to participate because your doctor's office may start offering the website to its patients in the future.

### DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

In this study, you will be asked to attend one group meeting (called a "focus group"). The meeting will last no more than 2 hours. In this meeting, you will be in a group with 8-10 other people. The focus group leader will show you the website and ask your opinions about it, including what you like about it, what you don't like about it, whether it is easy to understand, and whether you think it would be helpful to you.

### BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from participating, but the information we learn from people in this study may help us make the website better so it is more helpful to patients.

### PAYMENT FOR PARTICIPATION

You will receive \$25 in cash for participating in the study. The payment will be given at the end of the group session. In order to receive this payment, you will be required to complete a form called a "substitute W-9 form." Your social security number is required by federal law. It will not be included in any information collected about you for this research. Your social security number will be kept confidential and will only be used in order to process payment.

### CONFIDENTIALITY

Potentially identifiable information about you will consist of the audiorecording of the focus group and any notes taken during the session. This data is being collected only for research purposes. At the beginning of the session, all members will be asked to use first names only so that no full names are recorded. After the information from the recording is typed up and the transcript has been confirmed to be accurate, the recording will be destroyed.

All personal identifying information will be kept in password protected files, and these files will be deleted once all the focus groups for the study have been completed. The transcript of the group session, which will not contain any information that identifies you, will be kept indefinitely. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by the sponsor of the research, or by Virginia Commonwealth University. Personal information about you might be shared with or copied by authorized officials of the Department of Health and Human Services.

What we find from this study may be presented at meetings or published in papers, but your name will never be used in these presentations or papers.

## **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the group session.

## **QUESTIONS**

If you have any questions, complaints, or concerns about your participation in this research, contact:

**[Research Coordinator]  
[Phone number]  
[Email address]**

The researcher named above is the best person to call for questions about your participation in this study.

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research  
Virginia Commonwealth University  
800 East Leigh Street, Suite 300  
P.O. Box 980568  
Richmond, VA 23298  
Telephone: (804) 827-2157

Contact this number for general questions, concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at on the VCU website at <http://www.research.vcu.edu/irb/volunteers.htm>.