Attachment 6a

Research Participant Information Sheet, English

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Research Participant Information Sheet

Why is this study being done?
This is a study to improve our understanding of patients' cancer screening and follow-up experiences prior to their cervical cancer diagnosis. We know of no better way to learn about these experiences than to reach out to cancer survivors directly. You are being asked to take part in this study to help doctors, nurses, and researchers better measure and improve the health of women like you and to improve access to care in other women.

How was I selected?
The names of persons diagnosed with cancer in this state are reported to a cancer registry. Cancer registries were created to help find the causes and cures of cancer.

What is involved?
We want to better understand your experiences by hearing from you. If you decide to participate, we ask you to complete the enclosed survey in writing or during a phone call with us. The survey should take about 15 minutes to complete. The questions are about different topics, such as your cervical cancer screening history and follow-up of abnormal test results prior to your cancer diagnosis. You may complete the survey at your convenience and you may skip any questions you do not wish to answer, but we encourage you to answer all of the questions so that we can better understand your experiences.

To gain a better understanding of the medical care that you received prior to your diagnosis, we are also asking for your permission to access your medical records so that we can document your cervical cancer screening and follow-up. This type of information is recognized by doctors as being important for understanding and improving our knowledge about cervical cancer prevention.

You may choose to participate in the survey portion of this study only. After we have received your completed survey, you will be sent a $25 gift card in appreciation of your time.

Your participation is voluntary.
Your participation in this study is completely voluntary. Your decision to participate or not will not affect your current or future medical care and has no impact on your insurance. If you decide to participate, you can change your mind later and stop being in the study at any time.

What are the risks and benefits?
Some of the survey questions may be personal or sensitive and may make you feel uncomfortable. If you don't want to answer a question, you can skip it and go to the next question. Other risks of participating in the study may include loss of confidentiality; however, your information will be protected to the fullest extent possible. Privacy protections are described in the "Your information will be kept private" section of this Information Sheet.

There are no direct benefits to you from taking part in this research, but your participation could help researchers improve access to cancer care for others by better understanding how people who are diagnosed with cervical cancer receive medical care, what their perceptions of screening were prior to diagnosis, and how their perceptions may have impacted how often they were screened.

What other options are there?
You have the option to not take part in this study.

Your information will be kept private.
All information that you give is private, will only be used for research purposes, and will not be shared with your doctor or any other healthcare provider. All records that contain your name, telephone number, or other information that could identify you are kept separate from the survey forms and your medical record information. All records will be kept in locked file cabinets and computer files that are password protected. We will develop reports about the study results, but all reports will contain summarized information which means that no one will be able to be identified by our reports. The study staff will make every effort to ensure the privacy of the information you share with us.

Are there any costs?
There is no cost to you to be in the study.

What happens if you need care?
If you choose to participate in this study, we will ask you to answer questions on a written survey or complete a survey by telephone. This study does not involve any medical treatment or care. If you need care, you will be encouraged to contact your personal medical provider about resources that may be available to you to address any concerns that you may have. We cannot provide medical treatment or care.

Who can you call if you have questions or to request documentation of your participation?
You may contact *[cancer registry study coordinator]* at (800) ___-____ (toll-free) or (___) ___-____ with any questions or concerns about your participation in this study or to request documentation of your participation. If you have any questions about your rights as a study subject, you may contact the Institutional Review Board for the Protection of Human Subjects at *[cancer registry address and phone numbers]*.