Exploring Timeliness of Cancer Diagnosis in Persons with Physical Disability

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Who are we?
We are researchers from the Health Policy Research Center at the Mongan Institute at Massachusetts General Hospital. We are interested in looking at health care experiences of people who have difficulties with movement or have a mobility disability and who later in life develop cancer. This research study is sponsored by the National Institute of Health.

What is the purpose of this study?
We are trying to learn whether people who have mobility disability get the services they need and what can be done to make their health care experiences better.

Why do we want your participation?
We want to learn about the health care experiences of people who have difficulties with movement or have a mobility disability and who later in life develop cancer. We are looking to interview 20 volunteers who have had a mobility disability for at least one year preceding cancer diagnosis. We want to talk with you because:

- You appear to have had difficulty with movement or mobility
- You had non-Hodgkin lymphoma, prostate, colorectal, or ovarian cancer within the last ten years
- You are between 21-74 years old
- You speak English and live in the United States

How long will this take?
If you agree to participate, Lisa Iezzoni will interview you by telephone at a time that is good for you. This one-time interview will take 1 to 2 hours, but you can stop at any time.

Will I get paid?

Yes, we will mail you a $50 gift card after the interview in thanks for your time. We need your mailing address to get this gift card to you. It may take a few weeks for the gift card to arrive.

What are the risks to me?

We will be talking your health care experiences in this interview and you may feel uncomfortable answering some questions. This interview will also ask about your personal feelings about your health care experiences. Remember that participation in this research study is voluntary, and that you can refuse to answer any question or end the interview at any time. Participation in this study does not affect any medical care you choose to receive at a Partner’s health care provider now or in the future. None of the information you give us will be used in clinical care.

This interview will also be audio-recorded and transcribed. We will not talk about the names of the people who volunteer for this project. Your identity will be kept confidential. When the recording is being transcribed, your name will be replaced with a number. Only we will have access to and know which code belongs to you. These codes will be stored on Dr. Iezzoni’s computer, which is secure and password-protected. Other project staff will see your responses only when your identity is hidden by this code. No one will know what you said other than Dr. Iezzoni. We will destroy the recording when the project is completed in May 2020.

Questions?

If you have any questions, please contact Lisa Iezzoni or Nicole Agaronnik (contact information above).

If you’d like to speak to someone not involved in this research about your rights as a research subject, or any concerns or complaints you may have about the research, contact the Partners Human Research Committee at (857) 282-1900.
HIPPA Disclosure: We are required by the Health Insurance Portability and Accountability Act (HIPAA) to protect the privacy of health information obtained for research. This is an abbreviated notice, and does not describe all details of this requirement. During this study, identifiable information about you or your health will be collected and shared with the researchers conducting the research. In general, under federal law, identifiable health information is private. However, there are exceptions to this rule. In some cases, others may see your identifiable health information for purposes of research oversight, quality control, public health and safety, or law enforcement. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy.

THANK YOU!