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Attachment F: IRB Approved Consent Document

Background

Boston University Health and Disability Research Institute and YouGov are doing a research study. This study will test a series of questions that ask about your health and functioning.

Purpose

The purpose of this study is to test the consistency of scores generated from questions about your health and function when administered at different time points.

What Happens In This Research Study

You will be one of approximately 800 subjects to be asked to participate in this study.

This research study will be conducted by YouGov on behalf of Boston University Health and Disability Research Institute.

As a study participant you will be asked to answer questions about your functioning in daily life. You will be asked to complete the survey on your own using the internet. This survey will be administered at two time points about a week apart and should take 20 minutes to complete each survey. The information we collect is for research purposes only.

Risks and Discomforts

We expect that your participation will not cause you any discomfort. There may be unknown risks/discomforts involved. Study staff will update you in a timely way on any new information that may affect your health, welfare, or decision to stay in this study. There may be the potential for a small loss of confidentiality of the information you provide as part of this study; however, all measures possible will be taken to prevent this loss. Your name will not be used in any research publications and the information you provide will only be linked to you by a study identification number.

Potential Benefits

You will receive no direct benefit from your participation in this study. However, your participation may help the investigators improve upon the questions they are

asking about daily life functioning of adults.

Alternatives

Your alternative is to not participate in the study.

Subject Costs and Payments

There are no costs to you for participating in this research study. As part of the YouGov panel you will be given 1000 points to complete the first survey and 2000 points to complete the second.

Confidentiality

Information from this study may be reviewed by the Office of Human Research Protection as and the Institutional Review Board of Boston University Medical Center. Information from this study be used for research purposes and may be published; however, your name will not be used in any publications.

Subject's Rights

By consenting to participate in this study you do not waive any of your legal rights. Giving consent means that you have heard or read the information about this study and that you agree to participate. You will be given a copy of this form to keep.

If at any time you withdraw from this study you will not suffer any penalty or lose any benefits to which you are entitled.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 617-638-7207. If this study is being done outside the United States, you can ask the investigator for contact information for the local Ethics Board.

The investigator or a member of the research team will try to answer all of your questions. If you have questions or concerns at any time, or if you need to report an injury while participating in this research, contact Kara Bogusz at 617-638-1995.

Right to Refuse or Withdraw

Taking part in this study is voluntary. You have the right to refuse to take part in this study. If you decide to be in the study and then change your mind, you can withdraw from the research. Your participation is completely up to you. Your decision will not affect your being able to get health care at this institution or payment for your health care. It will not affect your enrollment in any health plan or benefits you can get.

If you choose to take part, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them as soon as possible.

The investigator may decide to discontinue your participation without your permission because he/she may decide that staying in the study will be bad for

you, or the sponsor may stop the study.