

RESEARCH CONSENT FORM

The Social Security Administration's Functional Assessment Study

OMB No.: 0925-XXXX

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Public reporting burden for this collection of information is estimated to be 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspects of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-XXXX). Do not return the completed form to this address.

H-31918- ANALYZING THE SSA EVALUATION PROCESS

Background

The Social Security Administration (SSA) along with the National Institutes of Health (NIH), Boston University (BU) and Westat are doing a research study. This study will test a set of questions about how applicants are functioning and see if it can improve the process that SSA uses to determine work disability. If you are able to do the study, then we will ask you to complete two surveys.

Purpose

The purpose of this study is to create a set of questions about claimant functioning (activities) and to see if it can improve the SSA disability application process. Answers to these questions will help to create a new questionnaire to assess functional ability and may improve the SSA disability application process.

You can decide if you want to take part in this study or not. Your decision will not affect in any way your current or any future SSA disability application.

What Happens In This Research Study

Your name was randomly chosen from a large group of people who applied for SSA work disability benefits. You will be one of about 12,000 people asked to take part in this study. As a study participant, you will be asked to answer questions about your functioning (activities) in two separate surveys at two different times. The first survey (Survey # 1) will take about 45-60 minutes to complete. You may choose to do the survey on your own using the internet, or you can do it over the telephone with an interviewer. When you have completed all the survey questions, we will send you a check for \$20 for your time. About 10 days after you complete Survey # 1, we will ask you complete a second survey (Survey # 2). Survey # 2 will take about 30-45 minutes to complete. Again, you may choose to do the survey on your own using the internet or you can do it over the telephone with an interviewer. When you have completed all the Survey # 2 questions, we will send you another check for \$30 for your time. Some data collected for this study will be used in the future as part of additional research efforts conducted at NIH. NIH will want to see how the survey results relate to SSA's determinations of disability. As part of this future research, NIH will use a case record identifier to track the decisions for all applicants who take part in this study. NIH will not use your name or your social security

number in the research.

The information we collect is for research purposes only. SSA will not know if you decide to take part in the study or not.

All of the research in this study will take place at Boston University and Westat. Westat is a survey research organization located in Rockville, MD. Westat will contact applicants chosen for the study, give them access to the questions, and provide payment when each survey is complete. Boston University is responsible for developing the questions and analyzing the data.

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 decision to stay in this study.

The information you provide will be kept confidential, and will not be disclosed to anyone but the researchers conducting this study, except as otherwise required by law.

Your name will not be used in any research publications and the information that you provide will only be linked to your name by a study identification (ID) number. The name and study ID numbers will be stored on secure servers at Boston University and Westat and will only be available to study staff.

Potential Benefits

You will receive no direct benefit from your participation in this study. However, your participation may help the researchers better understand how to improve the way the Social Security Administration determines work disability.

Alternatives

Your alternative is to refuse to take part in the study.

Subject Costs and Payments

There are no costs to you to be in this research study. You will receive \$20 for your time after completing Survey # 1 and you will receive an additional \$30 for your time after completing Survey # 2.

Securing Information

Any and all information you provide to us will be kept secure, to the extent provided by law. Information from this study may be reviewed and photocopied by state and federal regulatory agencies such as the Office of Human Research Protection as applicable, and the Institutional Review Board of Boston University Medical Center. Information from this study may be used only for research purposes and may be published; however, your name will not be used in any publications.

Subject's Rights

By consenting to take part 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 take part in the study. This copy of the consent form is yours to keep.

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.

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, contact Kara Bogusz at 617-638-1995 during the day and after hours.

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 stop at any time. Your participation is completely up to you. It will not affect your application for disability benefits.