

Appendix A: Informed consent form - revised



Next Generation of Enhanced Employment Strategies Project

Voluntary Consent to Participate in a Study

[PROGRAM NAME] IS PART OF A NATIONAL STUDY

[PROGRAM NAME]¹ is participating in the Next Generation of Enhanced Employment Strategies Project. This is a national study paid for by the U.S. Department of Health and Human Services [FOR SITES FUNDED BY SSA: and the Social Security Administration]. The study aims to identify promising programs to help people find jobs and become independent. A research organization called Mathematica is conducting the study. Researchers from other organizations could also work on the study in the future.

You have a choice about whether to be in this study. If you decide you want to be in the study, you will have a chance to receive [PROGRAM] services. If you decide you do not want to be in the study, then you cannot receive [PROGRAM] services right now.

WE WILL ASK YOU SOME QUESTIONS WHEN YOU JOIN THE STUDY

- o [PROGRAM] staff will ask you some questions about your name, date of birth, and Social Security number. [FOR SITES FUNDED BY SSA: Staff will also ask about your health and disabilities. Finally, staff will ask about your experiences with jobs and any benefits you get.] [FOR SITES NOT FUNDED BY SSA: Staff will also ask about your experiences with jobs and any benefits you get.] The questions take about 25 minutes to answer.

PARTICIPANTS IN THE STUDY WILL GO INTO ONE OF [NUMBER] GROUPS

- o After you answer those questions, a computer will put you into one of [NUMBER] groups. Which group you get into is determined by chance. Nothing you say will change which group you get into.
 - One group will be offered services from [PROGRAM]. In this group, [PROGRAM] staff can help you [DESCRIPTION OF PROGRAM].
 - TEXT FOR SITES WITH MORE THAN TWO GROUPS: Another group will be offered services from [LIMITED PROGRAM]. This includes [DESCRIPTION OF LIMITED PROGRAM].
 - [The second/third] group will not be offered services from [either] [PROGRAM] [nor LIMITED PROGRAM].

You may continue to receive all services and participate in all programs other than [PROGRAM] for which you are eligible. This is true for people in [both/all] groups.

WHAT IF YOU ARE IN THE GROUP THAT DOES NOT GET [PROGRAM] SERVICES?

- o If you are in the group that does not get [PROGRAM] [or LIMITED PROGRAM], you will still be in the study.

¹ Note to OMB: All fill-in brackets will be customized for each intervention to be tested.

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- o [IF THE PROGRAM WILL OFFER SERVICES LATER: [PROGRAM] may be able to offer services to you after the study ends]. [IF APPLICABLE: [PROGRAM] will save your name and address so [PROGRAM] staff can contact you after the study ends if they are able to offer services at that time.]
 - o You will be given a list of other organizations that might be able to help you.

WHAT INFORMATION ABOUT YOU WILL BE COLLECTED AFTER YOU JOIN THE STUDY?

- o The study team will contact you to take surveys either by telephone or online. These surveys will occur about [FOLLOW-UP 1 TIME PERIOD] and [FOLLOW-UP 2 TIME PERIOD] from now. Each survey should take about 50 minutes. [IF REQUIRED BY SCHOOL DISTRICT: If you complete the survey over the phone, we will record the phone call and use the recordings for quality control. We will destroy the recordings after 6 months.] You will get a \$40 gift card after finishing the first survey and a \$50 gift card after finishing the second survey. You can choose not to respond to the surveys.
- o We will ask some people in the [PROGRAM] group to do an interview about the program and work. This interview will take place either in person, by telephone, or by video. It will take about two hours [IF REQUIRED BY SCHOOL DISTRICT: and we will record the interview. If we pick you to do an interview, the study team will ask for your permission to participate and for us to record the interview. We will destroy the recordings at the end of the study.] You will get a \$60 gift card after finishing this interview. You can choose not to do the interview.
- o The study team might use information about you provided during the study to find new address information from other sources. This address information will be used to contact you about participating in the surveys.
- o [PROGRAM] will give information about you to the study team. This information may include [DEPENDING ON PROGRAM: your telephone number and address. It will also include the score on your eligibility screener, the organization that referred you to the program, your mental health diagnosis, and information about your participation in [PROGRAM] and your jobs.] [PROGRAM] and researchers will only use information we collect about you to improve [PROGRAM] or do research.
- o The study team will also collect information on [PRE-FILL FROM LIST RELEVANT TO PROGRAM]
 - Your earnings from the Social Security Administration and a database called the National Directory of New Hires
 - Benefits from the Social Security Administration
 - Benefits and contact information from Temporary Assistance to Needy Families (TANF); the Supplemental Nutrition Assistance Program (SNAP); General Assistance; Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); and the Unemployment Insurance (UI) program
 - Your use of other employment programs or services in your community
 - Child support that you owe and pay
 - Health care use through [state specific Medicaid program] (This would include information on doctor visits, hospital stays, emergency room use, and prescription medications.)
 - Involvement you have had with the criminal justice system
 - Information about your education from schools, school districts, state education agencies, and the National Student Clearinghouse
 - Housing, including participation in voucher programs
- o We will use your name, sex, date of birth, and Social Security number to get this information. The study team may collect this information from 2 years before to 20 years after the time you start the

study. The information will be used for research purposes only and will not be used to make decisions about whether you get benefits or the amount of benefits you get, now or in the future.

- o [FOR SSA FUNDED PROGRAMS: The Social Security Administration will do more research on your earnings and receipt of disability benefits. They will complete this research by 2040. They will use information such as your name, sex, date of birth, and Social Security number to try to locate you in their records. They will only use your information to do research. They will not use the information to make decisions about any benefits you receive from the Social Security Administration, now or in the future. The Social Security Administration will not contact you directly.]
- o We will also share the data from the study with other researchers to use in their work, but those data will not contain your name or any other information that could identify you.

HOW WILL WE KEEP YOUR INFORMATION SAFE?

- o Your name will never appear in a public report. We will never report information in a way that could be used to identify you.
- o All information about you will be used for research and evaluation purposes only or to improve [PROGRAM]. We will keep all information private and secure, unless the law requires otherwise, or you request release of your information in writing.
 - The researchers have a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, no one can force the researchers to share information that might identify you. This is true even if a court orders them to share information in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings.
 - The only exception is that researchers can share that you are in the study if a law requires it. Some examples are laws that require reporting if you tell the interviewers anything that suggests you are very likely to harm yourself, that you are planning to hurt another person, or that someone is likely to harm you.
 - A Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you want to release your information from the study to an insurer, medical care provider, or any other person not connected with the study, you must give consent to allow the researchers to release it.
- o [IF REQUIRED: Once all study data collection has been completed, all personally identifiable information collected for the study will be destroyed from Mathematica's servers using a secure deletion process.]

WHAT ARE THE RISKS OF BEING IN THE STUDY?

- o You might not like answering some questions. You can say no to answering any question you do not like. You can still be in the study even if you do not answer all the questions.
- o The study team will take many steps to keep all information private, but there is a small risk that someone else could see it. The data collected will include information about your jobs and earnings.
- o An organization called Health Media Lab protects your rights as someone in the study.

CAN YOU LEAVE THE STUDY?

- o You can leave the study at any time. To leave the study, you must call Mathematica toll-free at [TOLL-FREE NUMBER] and then write a message that you do not want to be in the study anymore. You can send this message to [MATHEMATICA STAFF PERSON] at [MATHEMATICA ADDRESS]. Any information we collect about you before you asked to leave the study will be part of the research.

If you have any questions, you can call Mathematica toll-free at [TOLL-FREE NUMBER]. You will receive a copy of this form for your records.

[IF REQUIRED BY SCHOOL DISTRICT: I have read the text above telling me about the instances in which I will be audio-recorded. Those instances include: (1) during the surveys and (2) if I am selected, during an additional interview about [PROGRAM] and my work. Audio recordings of the surveys will be used for quality control purposes and will be destroyed after 6 months. Audio recordings for the additional interview will be used for research purposes and will be destroyed at the end of the study.

YES, I agree to be audio recorded.

NO, I do not give consent to be audio recorded.]

[IF REQUIRED BY SCHOOL DISTRICT: SUMMARY OF STUDY CONSENT

In agreeing to be in the study, I understand that:

- o **While this project has been reviewed by [SCHOOL DISTRICT], [SCHOOL DISTRICT] is not conducting the project activities.**
- o The study will ask me to meet with [PROGRAM] staff. [PROGRAM] staff will ask me questions about my name, birthdate, Social Security number, health, and disabilities.
- o I will be in one of two study groups. One group will be offered [PROGRAM] services and one will not be offered [PROGRAM] services. Both groups can receive any other services for which they are eligible.
- o The study team will ask me to complete two surveys. I might receive a text message asking me to participate in these surveys. Participation is always optional.
- o Researchers will collect information about my jobs and disability benefits from government sources.
- o I understand that being in the study is voluntary. I can leave at any time, for any reason, without penalty.
- o I understand the study team will keep all information about me private. Researchers will use this information only for study purposes.]

Do you agree to participate in this study?

YES, I agree to be in this study.

NO, I do not give consent to be in this study.

[IF COLLECTED VIA HARD COPY]

Name (print): _____

Name (sign): _____ **Today's date:** _____