

Beneficiaries with Disabilities Interview Guide

Note: This interview guide is not a survey. It is a guide for researchers when conducting telephone interviews; the researchers will not use this verbatim.

1. *Verify beneficiary and functional limitation information from screener.*
2. *Review Informed Consent verbally over the phone before the interview. [Note: If the participant identified as having a cognitive impairment, conduct Post-Test after reviewing Informed Consent information. Determine whether the interview can proceed or not.]*
3. Can you recall what it was like when you first applied for Social Security benefits? We are particularly interested in the way people's disabilities (in your case, _____) affect their interactions with the Social Security Administration.
 - a. When did you first apply for Social Security benefits?
 - b. How did you apply: Online, by telephone, or in-person at a field office?
 - c. What was your experience like finding out what programs you were eligible for?
 - d. Did you receive adequate information about the various Social Security programs? Was it clearly written? Was it understandable to you?
4. I would like to ask you some questions about important information you receive from Social Security, such as notices you get by mail or over the phone:
 - a. Do they send you this information in the mail or do they call you on the phone?
 - b. *If notices by mail and person is blind or low vision:* Do they send you information in ordinary print, large print, Braille, or some other format?
 - i. *If ordinary print:* Did the Social Security Administration ever let you know that you have other options for receiving information, such as phone calls, large print, Braille, and other formats?
 - c. As a person with [type of disability], do you have any difficulty receiving important information, or [reading/hearing] or understanding the information?
 - d. Would you prefer to get information from Social Security in some other way? *Probe:* For example, [*mention these as appropriate:* by phone, over the Internet, on a computer disk, in Braille, in large print, or a tape recording].
 - e. What else could the Social Security Administration do to make important information easier for you to receive, read, and understand?

5. When you need to contact the Social Security Administration about your benefits, how do you usually do that? *Probe if necessary:* Do you call them, visit an office, or use the Internet?
6. *If not known, ask:* Do you use the Internet? *If no, skip to Q. 9.*
7. Where do you use the Internet? *Probe: Home, work, school, the library, a café, or somewhere else?*
8. Have you gone to the Social Security Administration's website in the past couple years?
If yes:
 - a. Were there any particular difficulties or barriers you had that were related to your [type of disability]?
 - b. Do you have any recommendations on how to make the Social Security Administration's website more user-friendly or easier to navigate for individuals with [type of disability]?
9. Have you gone to a Social Security Administration office in the past couple years?
If yes:
 - a. Were there any particular difficulties or barriers you had that were related to your [name of disability]?
 - b. Do you have any recommendations to make the Social Security Administration's field offices easier to navigate for individuals with [type of disability]?
10. Have you called the Social Security Administration in the past couple years?
If yes:
 - a. Were there any particular difficulties or barriers you had that were related to your [name of disability]?
 - b. Do you have any recommendations to make it easier for individuals with [type of disability] to communicate with the Social Security Administration by phone?
11. Considering everything that we have discussed, what would be the best way for the Social Security Administration to contact you, and for you to contact them?
12. How would you improve the way the Social Security Administration currently communicates and interacts with you?

Demographics

(Interviewer: emphasize these questions are optional):

13. *Verify age:* I recorded that you are _____. Is that correct?
14. *If not already, known:* What is your gender?
15. What state do you live in?
16. Would you describe yourself as living in a city, a suburb, a rural area, or something else?
17. Is there anything else you would like to share with me about your experience as a Social Security beneficiary?

INTERVIEWER: (read) Social Security estimated that this survey would take 45 minutes to complete. If you would like to send comments on this time estimate to Social Security, I can provide you with the mailing address. Would you like this address?

If yes, read the Paperwork Reduction Act statement below, and then go to closing. If no, go to closing.

Paperwork Reduction Act Statement - This information collection meets the requirements of 44 U.S.C. §3507, as amended by section 2 of the Paperwork Reduction Act of 1995. You may send comments on this 45-minute time estimate to: Social Security Administration, 6401 Security Blvd., Baltimore, MD 21235-6401.

INTERVIEWER: Thank you very much for participating in this study.

Needs Assessment of Social Security Beneficiaries with Disabilities Informed Verbal Consent Script

Use the following introduction for eligible participants:

Hi, this is (*researcher name*) from the University of California, San Francisco. We are conducting a survey on behalf of the Social Security Administration. The purpose of the survey is to evaluate whether Social Security's services for communicating with individuals who receive Social Security disability benefits are effective or need improvement. We previously determined that you were eligible and interested in taking part in a 30-45 minute phone interview. Are you still interested in talking with us over the phone?

If YES:

You told us previously that you are currently receiving Social Security benefits. Is this true?

If NO:

I'm sorry for the misunderstanding; thank you for taking the time to speak with me. Goodbye.

You also told us that you had some kind of disability: You said you were [*Choose one:* deaf, hard of hearing, blind, or of low vision; or that you had difficulty using your hands, a mobility impairment, a speech impairment, or a cognitive impairment]? Is this true?

If NO:

I'm sorry for the misunderstanding; thank you for taking the time to speak with me. Goodbye.

If YES

For this study, we would like to ask you some questions over the phone to find out more about your experience communicating with Social Security. We would like to know your communication preferences and any barriers you've experienced communicating with Social Security. We'd very much like your input although your participation in this survey is voluntary. You're free not to participate at all, to end the interview at any time, or to not answer any question that you feel is too personal. However, your participation will help Social Security evaluate and improve its services to beneficiaries with certain disabilities, including ways they may provide better access to their services.

You've given us your name, phone number, and email address so that we could contact you. We will not share this information with Social Security and we will destroy it at the end of the study. If you decide to participate in this interview, your answers will be kept private and they will not affect your benefits in any way. We may present the information you provide to us in reports to Social Security or in scientific presentations or publications, but the information will not contain any personally-identifiable information. Only researchers on this project will have access to the written notes and forms.

Do you have any questions?

*****If has a COGNITIVE IMPAIRMENT, follow POST TEST SCRIPT below to introduce additional set of questions to determine adequate understanding of study before obtaining informed consent.*****

Are you willing to participate in this phone interview? It will take about 30-45 minutes of your time.

If YES:

Great!!

[Proceed with the interview.]

If NO:

Thank you for taking the time to speak with me. Goodbye.

POST-TEST SCRIPT

INTERVIEWER: Do you remember when we first talked about the project I told you that I would be asking you some additional questions? We are doing this because you said you have [cognitive impairment/condition from screener] and we want to make sure you understand the study before taking part in it. Do you mind if I ask you those questions now?

IF YES: Conduct post-test

IF NO: I'm sorry you do not want to answer any additional questions—this means we will not be able to have you participate in the study. The reason we are doing this is to make sure you are aware of the risks and benefits of the study. In a way, we are doing this to protect you. We are not allowed to interview anyone who may not understand the study. Thank you for your interest.

AFTER POST-TEST

IF PASS: Thank you for answering these questions for us. This helps us make sure you are aware of the risks and benefits of the study.

IF NO PASS: Thank you for answering these questions for us. Unfortunately, some of the answer[s] you gave us showed that you did not understand the purpose of the study or the risks and benefits of it. Because of that, we do not feel it is right for us to include you in our study. This is to protect you and us. We follow strict guidelines from our University and a research oversight committee about making sure people in our studies

understands what it is about. We truly appreciate your interest and the time you took talking with us.

IF THEY ARE ANGRY: If you would like to speak to my supervisor you can contact:

Dr. Steve Kaye, PhD, at 415-502-7266, or toll-free at 866-727-9577 or the

UCSF Committee on Human Research (CHR), at 415-476-1814, 8 am to 5 pm, Monday through Friday.

University of California, San Francisco
Needs Assessment of SSA Beneficiaries with Disabilities
Evaluation for Consent to Act as a Research Participant¹

Cue #1: In summary, we're calling you so you can take part in a research study over the phone. What you tell us will not affect your Social Security benefits in any way.

Question #1: Will talking to me on the phone affect your Social Security benefits in any way?

Cue #2: This phone call is about how Social Security contacts you.

Question #2: What is this phone call about?

Cue #3: During the phone call you will be asked to share some of your experiences with Social Security.

Question #3: What will you be asked to share during this phone call?

Cue #4: There is a risk that I might ask you to talk about something that is embarrassing or personal.

Question #4: Tell me a possible risk of having this phone call with me.

Cue #5: This study may help Social Security serve others like you better.

Question #5: Who will this study help?

Cue #6: Remember, you can end this phone call at any time.

Question #6: If you want to end this phone call, when can you do this?

Question #7: Considering everything we've talked about, would you like to be a part of this study?

I will participate I will not participate Other:

ASSESSMENT: _____

Does Does not demonstrate adequate decision-making capacity.

Printed name of assessor

Signature of assessor

Date

4g. Do you have a learning disability? ___ Yes ___ No

4h. Do you have a developmental disability that affects your ability to learn?

___ Yes ___ No

4i. Do you have a cognitive condition that affects your ability to concentrate, remember things or make decisions?

___ Yes ___ No

5. In what state do you live? _____

FOR INTERVIEWER ONLY:

Eligibility:

Receives any type of SSA benefits & has at least one condition/disability.

If has a cognitive impairment:

"You are eligible to participate, but I will have to ask you more questions and obtain your informed consent before we do the actual interview. In the meantime, please review the Study Information Sheet that I will send to you, and feel free to contact me with any questions. You will also have ample time to ask questions when I call you back for the interview."

Is the participant eligible?

___ Yes ___ No

If yes, collect the following information and send him/her the Study Information Sheet:

Name:

Phone:

Email:

Time Zone:

Preferred time/day for a 30-45 minute phone interview:

Other notes (accommodation issues):

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

INFORMATION SHEET ON PARTICIPATION IN A RESEARCH STUDY

Study Title: Needs Assessment of Social Security Beneficiaries with Disabilities

This is a research study to help find out how the Social Security Administration (SSA) can improve how they communicate with beneficiaries who have disabilities. The SSA asked researchers at the University of California, San Francisco (UCSF) to interview SSA beneficiaries with disabilities. UCSF will be doing these interviews to see how these beneficiaries communicate with the SSA, what barriers they experience when communicating with the SSA, and what their preferred formats for communicating with the SSA are. The study researchers, Steve Kaye, Ph.D., Alice Wong, MS, and Melinda Neri, BA, Department of Social and Behavioral Sciences, UCSF, will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you identified yourself as a person with a disability who currently receives benefits from the Social Security Administration.

Why is this study being done?

The purpose of this study is to conduct interviews to explore how SSA beneficiaries with different types of disabilities interact and communicate with the SSA, what barriers they experience when communicating with the SSA, and what their preferred formats would be when communicating with the SSA.

The study is being funded by the Social Security Administration (SSA). The SSA pays for the conduct of this study, including part of the salaries of Dr. Kaye, Ms. Wong and Ms. Neri.

How many people will take part in this study?

About 140 people will take part in this study.

What will happen if I take part in this research study?

If you agree to participate, the following will occur:

- The researcher will interview you over the phone for about 30-45 minutes. The researcher will ask you about your experiences communicating and interacting with the SSA. You will also be asked about any barriers you have experienced during your interactions and communications with the SSA, as well as your preferences for communicating with the SSA.
- The researcher will take detailed notes during the phone conversation.
- After the interview, the researchers will type up the notes and remove any mention of names or other personal identifiers.
- **Study location:** All of these procedures (i.e., the interviews) will be done via the telephone and therefore at a location that is most convenient for you – most likely your home, office, or place of work.

How long will I be in the study?

Participation in the study will take a total of about 30 – 45 minutes.

Can I stop being in the study?

Yes. You can decide to stop the interview at any time. Just tell the study researcher right away if you wish to stop being in the study or if you do not want to continue answering any or all of the interview questions.

Also, the study researcher may stop you from taking part in this study at any time if he or she believes it is in your best interest, if you do not follow the study rules, or if the study is stopped.

What side effects or risks can I expect from being in the study?

- There is a possibility that some of the discussion topics or interview questions may cause emotional discomfort or embarrassment for you, but you are free to decline to answer any question and end the interview at any time.
- The contact information (your name, email address, and phone number) that you personally provide will be handled as confidentially as possible. We will not share your contact information with Social Security and we will destroy it at the end of the study. Your contact information will not be kept with the answers you provide during the interview, but there is minimal risk that your answers could be associated with your contact information. Although we will protect your contact information and keep it private, there is always a risk that it could be stolen or breached.
- For more information about risks, ask one of the researchers.

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However, it is our hope that over time, this research will help to improve how the SSA interacts and communicates with their beneficiaries who have disabilities.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. It will not affect your Social Security benefits in any way.

Will information about me be kept private?

We will not share your contact information with Social Security and we will destroy it at the end of the study. We may present information you give to us during the interview in reports to Social Security or in scientific presentations or publications, but the materials will not have any information that could identify you.

Your contact information will not be kept with the answers you provide during the interview, but there is minimal risk that your answers could be associated with your contact information. Although we will protect your contact information and keep it private, there is always a risk that it could be stolen or breached.

Organizations that may look at and/or copy the de-identified research records for research, quality assurance, and data analysis include:

- The UCSF Committee on Human Research

What are the costs of taking part in this study?

There is no cost for you to take part in this study. You will not be charged for any part of this study.

Will I be paid for taking part in this study?

No, you will not be paid for taking part in this study.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way. It will not affect your Social Security benefits in any way.

Who can answer my questions about the study?

You can talk to the researcher(s) about any questions or concerns you have about this study. Contact the researcher(s), Steve Kaye, PhD at 415-502-7266, or toll-free at 866-727-9577; Alice Wong at 415-502-7097, or Mel Neri at 415-476-5164.

If you have any questions, comments, or concerns about taking part in this study, first talk to the researchers (above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights).

You can reach the CHR office at **415-476-1814**, 8 am to 5 pm, Monday through Friday, Pacific Standard Time. Or you may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

CONSENT

You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

Needs Assessment of Social Security Administration Beneficiaries with Disabilities

University of California, San Francisco (UCSF)

Are you a person with a disability (including cognitive, hearing, vision, or physical) who receives benefits from the Social Security Administration? Benefits can mean SSI, SSDI, or retirement.

If so, we'd like to talk with you!!

Researchers at the UCSF Disability Statistics Center want to know more about your experience applying for Social Security benefits and your interactions with the Social Security Administration. We are conducting a needs assessment for the Social Security Administration so that they can communicate better with their beneficiaries who have disabilities. Phone interviews will be approximately a 30-45 minutes long.

For more information, or to participate, please call this toll-free number: 1-855-209-9538

Please speak clearly and slowly to leave your name and number. A UCSF researcher (Mel) will get back in touch with you to tell you more about this study.

Or you can email:

alice.wong2@ucsf.edu

Alice Wong, Staff Research Associate II
UCSF Disability Statistics Center