Consent Form for Participation in Research

Study Title: AphasiaBank

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Purpose of this Study

The purpose of the study is to to gather data to be placed in a computerized data bank for the study of language and communication in people with aphasia.

Procedures

You will be asked to describe pictures, discuss events in your life, and tell a story. You will also complete a repetition test and 3 standardized measures of aphasia – a portion of the Western Aphasia Battery, the short form of the Boston Naming Test, and the Verb Naming Test from the Northwestern Assessment of Verbs and Sentences-Revised.

The session will be videotaped for later transcription and analysis. In addition, you will be asked to provide relevant demographic information.

The research will be take approximately 1.5 hours of your time and will be done at your regular stroke group meeting place.

Participant Requirements

Individuals with aphasia resulting from a stroke are eligible to participate in this study.

Risks

The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life or during normal conversation, which may include frustration, fatigue, and/or boredom.

Benefits

There may be no personal benefit from your participation. However, by participating you will allow us to improve our understanding of aphasia and we will be able to give you information regarding your strengths and weaknesses in communication.

Compensation & Costs

You will receive $40 as well as free parking during testing. There will be no cost to you if you participate in this study.

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Confidentiality

By participating in the study, you understand and agree that Carnegie Mellon may be required to disclose your consent form, data and other personally identifiable information as required by law, regulation, subpoena or court order. Otherwise, your confidentiality will be maintained in the following manner:

Your data and consent form will be kept separate. Your consent form will be stored in a locked location on Carnegie Mellon property and will not be disclosed to third parties. By participating, you understand and agree that the data and information gathered during this study may be used by Carnegie Mellon and published and/or disclosed by Carnegie Mellon to others outside of Carnegie Mellon. However, your name, address, contact information and other direct personal identifiers in your consent form will not be mentioned in any such publication or dissemination of the research data and/or results by Carnegie Mellon.

The researchers will take the following steps to protect participants' identities during this study: (1) All research data will be assigned a participant code; (2) The researchers will record any data collected during the study by participant code, not by name; (3) Original recordings and data files will be stored in a secured location accessed only by authorized researchers; (4) Access to the audio and video language transcript database is password protected, accessed only by authorized CMU researchers and AphasiaBank members.

Optional Permission

1. I understand that the researchers may want to use a short portion of any video or audio recording for illustrative reasons in presentations of this work for scientific or educational purposes. I give my permission to do so provided that my name will not be used.

☐ YES ☐ NO (Please initial here _____)

2. I give my permission to allow AphasiaBank to request release of my MRI and CT brain scans for further analysis.

☐ YES ☐ NO (Please initial here _____)

Rights

Your participation is voluntary. You are free to stop participation at any point. Refusal to participate or withdrawal of your consent or discontinued participation in the study will not result in any penalty or loss of benefits or rights to which you might otherwise be entitled.

The experimenter may at his/her discretion remove you from the study for any reason. In such an event, you will not suffer any penalty or loss of benefits or rights to which you might otherwise be entitled.

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Right to Ask Questions & Contact Information
If you have any questions about this study, you should feel free to ask them now. If you have questions later, desire additional information, or wish to withdraw your participation please contact the Principle Investigator by mail, phone or e-mail in accordance with the contact information listed on the first page of this consent.

If you have questions pertaining to your rights as a research participant; or to report objections to this study, you should contact the Research Regulatory Compliance Office at Carnegie Mellon University. Email: irb-review@andrew.cmu.edu . Phone: 412-268-1901 or 412-268-5460.

Voluntary Consent
By signing below, you agree that the above information has been explained to you and all your current questions have been answered. You understand that you may ask questions about any aspect of this research study during the course of the study and in the future. By signing this form, you agree to participate in this research study.

_____ _____
PARTICIPANT SIGNATURE DATE

I certify that I have explained the nature and purpose of this research study to the above individual and I have discussed the potential benefits and possible risks of participation in the study. Any questions the individual has about this study have been answered and any future questions will be answered as they arise.

_____ _____
SIGNATURE OF PERSON OBTAINING CONSENT DATE

Adult Assent
If you cannot give legal consent to take part in this study because you may have trouble reading or understanding this consent form, then the researcher will ask for your assent. Assent is your agreement to be in the study. The researcher will explain the study to you in words that you can understand. You should ask questions about anything you don't understand. Then you should decide if you want to be in the research study. If you want to participate, you or someone who can sign a legal document for you must also give their permission and sign this form before you take part.

By signing below, you agree to participate in this study:

_____
PRINT PARTICIPANT'S NAME

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PARTICIPANT'S SIGNATURE DATE

Consent of Guardian / Representative

If you have authority to consent on behalf of the above named participant, please print your name

_____ and indicate your relationship to the participant:

_____ The participant's legal guardian

_____ A surrogate

_____ A durable power of attorney

_____ A proxy

_____ Other, please explain:_____

By signing below, you warrant that you have the authority to make decisions on behalf of the participant. You agree that the above information has been explained to you and all your current questions have been answered. You understand that you may ask questions about any aspect of this research study during the course of the study and in the future. By signing below, you consent to the participant's involvement in this study.

SIGNATURE OF LEGALLY AUTHORIZED REPRESENTATIVE DATE

I certify that I have explained the nature and purpose of this research study to the above individual and I have discussed the potential benefits and possible risks of participation in the study. Any questions the individual has about this study have been answered and any future questions will be answered as they arise.

SIGNATURE OF PERSON OBTAINING CONSENT DATE

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