

CONSENT FORM

Database for Future Contact: Older Adults for Cognitive Tasks

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This consent form describes a research database, what you may expect if you decide to take part and important information to help you make your decision. Please read this form carefully.

The study staff will explain this study to you. Please ask questions about anything that is not clear before you agree to participate. You may take this consent form home to think about and discuss with family or friends.

- Being in this database is voluntary – it is your choice.
- If you join this database, you can change your mind and stop at any time.
- If you choose not to take part, your routine medical care will not be changed in any way.
- There are risks from participating and you should understand what these mean to you.

Introduction & Purpose

The researchers in the CogT Lab at the University of Rochester have created a database (a list) of individuals who are interested in taking part in future research studies about cognitive aging. People included in the database will be contacted when a new study starts to see if they are interested in participating.

Description of Database

If you decide to be included in the database, your contact information and information from your research records will be placed in this list. This will include information such as name, date of birth, diagnosis of cognitive status, phone number(s) and best time to reach you, address, and email. In addition to this information, we will also ask you to complete two short questionnaires regarding cognitive abilities. This information will help us determine whether a particular research study would be a good fit for you. Researchers may then contact you in the future about new research on cognitive aging. If you are contacted, you can decide at that time whether or not you are interested in participating in the study. Being included in the database does not mean you will be enrolled in the study; rather, you are only agreeing to be contacted about future research studies.

You may change your mind and have your name, and any additional information that was collected, removed from the database at any time by contacting the study team using the information below. You would like to be removed from the

database. Otherwise, after 5 years, you will automatically be removed from the database and no longer contacted.

Risks of Participation

Participation in research may involve some loss of confidentiality. None of your information will be used for research without your permission. Your contact information will not be shared with anyone outside the study team.

Benefits of Participation

You might not benefit from being in this research database.

Costs/Payments

There will be no cost to you to participate in this database. You will not be paid for participating in this database.

Confidentiality of Records

The University of Rochester makes every effort to keep the information collected from you confidential. In order to do so, we will obtain the minimum information necessary to match interested subjects to ongoing studies. The database will be kept in a password-protected file on a limited access shared drive and will be restricted to individuals listed on this application. This information will be kept for five years. Sometimes, however, researchers need to share information that may identify you with people that work for the University, regulators or the study sponsor. If this does happen, we will take precautions to protect the information you have provided. Results of the research may be presented at meetings or in publications, but your name will not be used.

If you have never received a copy of the University of Rochester Medical Center (URMC) and Affiliates Notice of Privacy Practices, please ask the investigator for one.

What information may be used and given to others?

The study doctor will get your personal and medical information. For example:

- Research records
- Records about phone calls made as part of this research
- Records about your study visits

Who may use and give out information about you?

- The study doctor and the study staff
- URMC and Affiliates

Your information may be given to:

- The Department of Health and Human Services
- The University of Rochester

Why will this information be used and/or given to others?

- To do the research
- To study the results
- To see if the research was done right

If the results of this study are made public, information that identifies you will not be used.

What if I decide not to give permission to use and give out my health information?

Then you will not be able to be in this research study.

May I review or copy my information?

Yes, but only after the research is over.

How long will this permission be valid?

This permission will last indefinitely.

May I cancel my permission to use and disclose information?

You may cancel your permission to use and disclose your health information at any time. You do this by sending written notice to the study doctor. Upon receiving the written notice, the study team will no longer use or disclose your health information and you will not be able to stay in this study. Information that has already been gathered may need to be used and given to others for the validity of the study.

May I withdraw from the study?

If you withdraw your permission to be in the study, no new health information identifying you will be gathered after that date. Information that has already been gathered may still be used and given to others.

Is my health information protected after it has been given to others?

There is a risk that your information will be given to others without your permission.

Contact Persons

For more information concerning this research or if you feel that your participation has resulted in any emotional or physical discomfort please contact: Dr. Vankee Lin at (585) 276-6002.

Please contact the University of Rochester Research Subjects Review Board at 265 Crittenden Blvd., CU 420315, Rochester, NY 14642, Telephone (585) 276-0005 or (877) 449-4441 for the following reasons:

- You wish to talk to someone other than the research staff about your rights as a research subject;

- To voice concerns about the research;
- To provide input concerning the research process;
- In the event the study staff could not be reached.

Voluntary Participation

Taking part in this research database is voluntary. You are free not to take part or to withdraw at any time, for whatever reason. No matter what decision you make, there will be no penalty or loss of benefit to which you are entitled. In the event that you do withdraw from this database, the information you have already provided will be kept in a confidential manner.

SIGNATURE/DATES

After reading and discussing the information in this consent form you should understand:

- Why this database is being maintained;
- What will happen during participation;
- Any possible risks and benefits to you;
- How your personal information will be protected;
- What to do if you have problems or questions about this database.

Subject Consent

I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I agree to participate in this database. I have received (or will receive) a signed copy of this form for my records and future reference.

Subject Name (Printed by Subject)

Signature of Subject

Date

Person Obtaining Consent

I have read this form to the subject and/or the subject has read this form. I will provide the subject with a signed copy of this consent form. An explanation of the research was given and questions from the subject were solicited and answered to the subject's satisfaction. In my judgment, the subject has demonstrated comprehension of the information. I have given the subject adequate opportunity to read the consent before signing.

Name and Title (Print)

Signature of Person Obtaining Consent

Date