1. General Information

Study title:
Center for Aging and Translational Research Participant Registry

Person in Charge of Study (Principal Investigator):
Dr. Scott Strath, PhD
Director
Center for Aging and Translational Research
College of Health Sciences & Helen Bader School of Social Welfare

2. Study Description

You are being asked to participate in a research study. Your participation is completely voluntary. You do not have to participate if you do not want to.

Study description:
The purpose of this study is to create and maintain a research participant database of those individuals who are interested in learning about and potentially participating in future studies being conducted by scientists affiliated with the Center for Aging and Translational Research. This study is being conducted at the University of Wisconsin-Milwaukee. Five thousand people (ages 18-90+ years) will become part of this participant database and you will commit up to 15 minutes of your time to learn about the project.

3. Study Procedures

What will I be asked to do if I participate in the study?
If you agree to participate you will be asked to:

- Read and sign this informed consent document allowing us to contact you at a future date to inform you of new research opportunities/protocols.
- Provide us with your name, address, phone number, and/or email address, which will be stored in a secure, password protected electronic database.
• Complete a short enrollment questionnaire containing 18 questions about your health status and caregiver status. The questions will be used for screening for whether you are eligible to participate in future studies.

What happens after I enroll in the participant registry?
• When Center Scientists are starting a new study, they will contact the Center to find out if any individuals in the participant registry database are eligible to participate in their new study.
• The Center will use the Center Scientists’ criteria to see who might be eligible to be part of the study. The Center staff will create a list of potential individuals who could participate in the study, and will give a copy of the list to the Center Scientist.
• A member of the study team, such as the Center Scientist or a student assistant, will contact the individuals on the list to see if they would like to participate in the new study. If you are contacted about participating in a new study, you can decide whether or not you would like to be part of the study.
  o If you want to be part of the new study, a member of the study team will explain the study and everything that you would have to do to be part of the study.
  o If you do not want to be part of the new study, you can say that you do not want to be in the study, and you will not be contacted again about that study.

4. Risks and Minimizing Risks

What risks will I face by participating in this study?
• There are minimal risks associated with providing health status information through the enrollment questionnaire.
• You do not have to answer any questions that you do not want to answer.
• All health status information will be stored in a secure location without your name attached to it. Only the PI, Co-Investigator and authorized Center research personnel (such as student research assistants) will have access to the data collected by this study.
• If you qualify for a new study, Center Scientists will have access to your contact information.
• You can choose to stop participating in the registry at any time, and we will stop contacting you about participating in future studies.
5. Benefits

Will I receive any benefit from my participation in this study?
- There are no benefits to you other than to further research.

6. Study Costs and Compensation

Will I be charged anything for participating in this study?
- You will not be responsible for any of the costs from taking part in this research study.

Are subjects paid or given anything for being in the study?
- You will not be compensated for taking part in this research study.
- Future studies for which you are eligible may include compensation for participation in research activities.

7. Confidentiality

What happens to the information collected?
All information collected about you during the course of this study will be kept confidential to the extent permitted by law. The health information collected through the enrollment questionnaire will be used for screening purposes only for potential inclusion or exclusion from future studies. Only the PI, Co-Investigator and authorized Center research personnel (such as student research assistants) will have access to the data collected by this study. If you qualify for a new study, Center Scientists will have access to your contact information. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study’s records.

Your contact information will be documented within a password protected electronic database housed within the Center for Aging and Translational Research. Additionally, all contact information collected during the time you sign the informed consent will be stored in a locked cabinet as well as electronically. The health status information collected via the enrollment questionnaire will be stored separately from all contact information.
8. Alternatives

Are there alternatives to participating in the study?
- There are no known alternatives available to you other than not taking part in this study.

9. Voluntary Participation and Withdrawal

What happens if I decide not to be in this study?
Your participation in this study is entirely voluntary. You may choose not to take part in this study. If you decide to take part, you can change your mind later and withdraw from the study. You are free to not answer any questions or withdraw at any time. Your decision will not change any present or future relationships with the University of Wisconsin Milwaukee.

If you decide to enroll in the participant registry now, and later decide that you do not want to be contacted regarding future studies, we will remove you from the registry and you will not be contacted about any additional future studies. If you would like to be removed from the registry, please email catr-community@uwm.edu with the subject line “Remove From Registry” and include in the body of the email your name and phone number so that we can remove the correct record from the database. Alternatively, you may call the CATR office at 414-229-7319 and ask to be removed from the registry. The person who answers the phone will ask for your name and phone number so that we can remove the correct record from the database.

In addition, you have the right to refuse to participate in any future study, but still remain part of the participant registry database to be contacted about other studies. If you do not want to participate in a study, you can inform the person who contacts you that you do not want to be part of that study.
10. Questions

Who do I contact for questions about this study?
For more information about the study or the study procedures or treatments, or to withdraw from the study, contact:

Dr. Scott Strath, PhD
Director
Center for Aging and Translational Research
University of Wisconsin-Milwaukee
P.O. Box 413
Milwaukee, WI 53211
(414) 229-7319
catr-community@uwm.edu

Who do I contact for questions about my rights or complaints towards my treatment as a research subject?
The Institutional Review Board may ask your name, but all complaints are kept in confidence.

Institutional Review Board
Human Research Protection Program
Department of University Safety and Assurances
University of Wisconsin – Milwaukee
P.O. Box 413
Milwaukee, WI 53201
(414) 229-3173
11. Signatures

Research Subject’s Consent to Participate in Research:
To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study, you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read or had read to you this entire consent form, including the risks and benefits, and have had all of your questions answered, and that you are 18 years of age or older.

_______________________________________
Printed Name of Subject/ Legally Authorized Representative

_______________________________________  __________
Signature of Subject/Legally Authorized Representative    Date

Principal Investigator (or Designee)
I have given this research subject information on the study that is accurate and sufficient for the subject to fully understand the nature, risks and benefits of the study.

_______________________________________  __________________
Printed Name of Person Obtaining Consent   Study Role

_______________________________________  __________
Signature of Person Obtaining Consent       Date