

PALS Consent: Registry Enrollee

PALS stands for Study Partner Availability Limitations Study. PALS is an observational study. It is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. You are being asked to join this study because you previously enrolled in the C2C Registry or Penn Brain Health Registry. Many Alzheimer's disease studies require people to enroll with a "study partner" who can accompany them to some research visits. We are interested in learning more about how this study partner requirement affects willingness and availability to participate in research. Your participation is voluntary, which means you can choose whether or not to participate. Participation in this study is not a requirement of the registry.

The goal of this study is to interview people who may be interested in participating in Alzheimer's disease research to understand if they have someone who might be willing and able to accompany them to research visits—that is, to be their "study partner." You will be one of 90 people participating in this study. Your participation will involve one telephone interview, approximately 45-60 minutes in length. You will be asked to participate in the telephone interview at a time that is convenient to you. We just ask that you arrange to participate in the interview at a time when you can be in a private space. During the interview, you will be asked about who might be able to join you for research visits, and whether you would be willing to ask them to do that. We will also ask you if this person might be willing to participate in PALS as well so that we can understand the views of potential study partners.

PALS Consent: Registry Enrollee

The conversation will be audio recorded and transcribed. Your name and any identifying information will be removed from the interview when it is transcribed. You will be assigned a unique ID number. The link between your name and ID number will be kept in a separate database that can only be accessed by the study team. We will take extensive precautions to protect your privacy. A key containing each participant's name, study ID number, and contact information will be kept in on a secure server until study procedures are completed and the data have been checked for completeness and accuracy. After this, the audio recording will be destroyed. The de-identified data (the transcript without your personal information) may be stored and distributed for future research studies.

There are no known health risks to your participation in this study. We expect that the interview will be similar to topics you might discuss with your family and friends. If you become tired during the course of answering our questions, you can take a break or stop the interview at any time.

While we take many steps to protect the information you share with us, there is the possibility that someone around you may hear and repeat what you say. We will do our best to make sure that your personal information will be kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used, though, we may use selected, anonymized quotes from your interview.

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This study is expected to end after all participants have completed all interviews, and the data has been analyzed. Your participation will be completed after your interview. You are free to leave the study at any time. Withdrawal will not interfere with your current or future participation in other studies. You may also withdraw or take away your permission to use and disclose your information at any time.

There is no direct benefit to you, though some people might find it beneficial to know they are contributing to Alzheimer's disease research. Your participation could help us understand how we can design future studies to maximize who can participate. Your participation is completely voluntary. There is no penalty if you choose not to join the study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future.

There are no costs associated with participating in the study. You will receive a \$25 Amazon e-gift card for your participation in the interview.