BENJAMIN ROSE INSTITUTE ON AGING
CONSENT FOR INVESTIGATIONAL STUDIES

Project Title: Adaptation of the SHARE for Dementia Intervention for African American Dyads

Principal Investigator: Silvia Orsulic-Jeras DYAD VERBAL CONSENT FORM

Purpose/Introduction
Hello, this is (NAME) from the Benjamin Rose Institute on Aging. The reason for my call is invite you to participate in an intervention program that is designed to facilitate communication about care preferences between you and your loved one to provide you with resources to help you manage aging-related challenges should they arise. The purpose of this program is to examine how well the intervention helps to enhance overall well-being by focusing on various areas of your life.

Study Procedures
For this study your participation will include one initial interview and one follow-up interview at the end of the study (approximately 60 minutes each). After your first interview, you and your loved one will be randomly placed into one of two groups:

1) Group 1 will receive up to six, 60- 75- minute planning sessions with a trained professional who will help you learn about memory loss, local resources that may be helpful to you, and ways to help you improve communication. These sessions can take place remotely from your home or another location if you prefer.
2) Group 2 will receive a single, standardized educational and resource session with a trained professional. Those in Group 2 will receive a packet of information containing information relevant to their care situation.

As mentioned above, you and your loved one are also being asked to participate in two research interviews. These interviews should take approximately 60 minutes to complete. The *first interview* will take place at the start of your participation and the *second interview* will take place approximately eight to ten weeks after you started participation in the study. During these interviews, you will be asked about your experiences with your family, your physical and emotional well-being, as well as your ideas about types of assistance that might be useful to you.

You can expect to participate in this study for approximately 12 weeks. Your participation may be terminated if you are unable to schedule or attend most of the sessions within this approximate time or your care situation changes. You may voluntarily end your participation in the program at any time.

Risks
The potential risks to you from participating in the program include the possibility of an adverse emotional or psychological reaction to portions of the assessment interviews, sessions or telephone contacts that may raise sensitive issues for some participants. The interviewers and professionals you will be working with have been trained to recognize and address any signs of distress that you may have during your interviews or information sessions. If at any point during the interviews or information sessions you become upset or agitated, the interviewer and/or professional may suggest ending the visit or call and offer to continue at a later time. If a major issue arises that the interviewer and/or professional is unable to handle, you may wish to seek professional assistance through Benjamin Rose Eldercare Services Institute or through another social service agency that we can refer you to. If some of the questions asked during the interviews are upsetting or you feel uncomfortable answering them, you may skip them and ask to go to the next question.

Benefits
There is no direct benefit to you by participating in this research study. Participation in this study may aid in improving information and services for persons with chronic conditions and their families.

Alternatives to Participation
Because of the nature of this research, the only alternative is not to participate in this study.

Financial Information
There is no cost to you for participation in this study.

Confidentiality
All information you give will be kept strictly confidential unless it concerns you or your loved one being abused, neglected, or exploited by another person. Our staff are required by law (Ohio Revised Code 5101.60) to report such concerns to the Adult Protective Services unit of the County Department of Job and Family Services. The information collected as part of this research, even if identifiers are removed, will not be used or distributed for future research studies.

Compensation/Cost
Each care partner participant will receive twenty-five dollars ($25) for participation in the program, a total of $50 per dyad. One check ($25 total) will be mailed to each participant from Benjamin Rose to your address within two weeks after you have completed your last assessment interview.

Summary of your rights as a participant in a research study
Your participation in this research study is voluntary. Refusing to participate will not alter your usual health care or involve any penalty or loss of benefits to which you are otherwise entitled. If you decide to join the study, you may withdraw at any time and for any reason without penalty or loss of benefits. If information generated from this study is published or presented, your identity will not be revealed. In the event new information becomes available that may affect the risks or benefits associated with this study or your willingness to participate in it, you will be notified so that you can decide whether to continue participating.

Disclosure of your study records
Efforts will be made to keep the personal information in your research record private and confidential, but absolute confidentiality cannot be guaranteed. The sponsor of the program may also review your records. If your records are reviewed your identity could become known. The information collected as part of this research, even if identifiers are removed, will not be used, or distributed for future research studies.

Contact information
(NAME) has described to you what is going to be done, the risks, hazards, and benefits involved. The Principal Investigator, Silvia Orsulic-Jeras, can also be contacted at (216) 373-1625.

Signature

Providing verbal consent indicates that you have been informed about the research study in which you voluntarily agree to participate; that you have asked any questions about the study that you may have; and that the information given to you has permitted you to make a fully informed and free decision about your participation in the study. By providing consent, you do not waive any legal rights, and the investigator(s) or sponsor(s) are not relieved of any liability they may have. A copy of this consent form will be provided to you.

The person listed below gave verbal consent to participate in this study.

_____ Date_____
Printed Name of Participant

_____ Date_____
Signature of Person Obtaining Consent

_____ Date_____
Signature of Principal Investigator (Affirming subject eligibility for the study and that informed consent has been obtained.)