FOCUS GROUP VERBAL CONSENT SCRIPT

Enhancing Triadic Communication About Cognition for Older Adults with Alzheimer's Disease or Related Dementias Facing a Cancer Management Decision – Focus Groups

Hi, my name is _____. I'm working on a study being conducted Dr. Allison Magnuson from the University of Rochester's Department of Medicine. Do you have a few minutes to discuss the study?

- If yes, continue below.
- If no, but the potential subject is interested in participating, determine a better time to call back to discuss the study. ▯ If no, thank them for their time.

We are inviting you to take part in this study because we are interested in your thoughts about an intervention to improve communication about cognition in the context of cancer treatment for older adults. Alzheimer's Disease and Related Dementias are prevalent aging-related conditions in older patients with cancer. For older adults with dementia and cancer, medical decision making is more complex. A geriatric assessment-based communication tool can increase conversations about aging-related conditions in cancer care. However, this communication tool is not specific for dementia or cognitive concerns. The purpose of this study is to gather perspectives of key stakeholders through focus groups, in order to help with refining the geriatric assessment-based communication tool for older patients with cancer and dementia.

If you decide to take part in this study, you will be asked to complete a brief questionnaire about your sociodemographic information. This form will gather your name, age, race, ethnicity, and information about the perspective you are offering during the focus group. For clinicians this will include details about the number of years in practice and the approximate number of patients you see weekly. For caregivers, this will include information about the number of years in the caregiving role. For cancer survivors, this will include information about the time since your cancer diagnosis and general information about the type of treatment previously received (e.g. surgery, radiation, chemotherapy, other). You will then be asked to particulate in a focus group. We estimate the focus group will be about 1 hour in duration. We will ask your permission to contact you after this in the event we have follow-up questions. The study coordinator may contact you by email or phone regarding scheduling the focus group session as well as to provide the Zoom link for joining the focus group session. The focus group session will be held virtually through Zoom.

We estimate that approximately 40 will take part in this study. Your participation will last about 3 months.

An anticipated risk to subjects is loss of privacy/breach of confidentiality. All efforts have been made to mitigate loss of privacy. We are using the University of Rochester's HIPAA-compliant Zoom platform. Subjects will provide their email address in order to be sent a zoom link for the focus group. The Zoom link for focus group participation will be individually emailed to each subject and there will be no sharing of emails of other focus group participants. If you are concerned about a privacy aspect from participating in a focus group, an individual interview is an alternative participation option. Another anticipated risk to subjects is potential distress resulting from topics discussed in the focus group. In the event of distress, the PI would be available to speak with subjects and provide a referral to social work and other support resources as needed.

Use of E-mail in Research
You will receive communications about this study via email messaging. Email communications between you and the study team may be filed in your research record.

Email communications may be sent or received in an unencrypted (unprotected) manner. Therefore, there is a risk that the content of the communication, including your personal information, could be shared beyond you and the study team. Your consent to participate in this study indicates that you understand this risk. The University of Rochester is not responsible for any interception of messages sent through email.

The University of Rochester is receiving payment from the National Institute on Aging for conducting this research study. You will be paid $75 for participating in this study. There will be no cost to you to participate in this study. For this study we use a subject payment system called Advarra Participant Payments. The system allows three ways to provide payment. You can choose: a reloadable debit card; direct deposit; or mailed paper checks. The study team will help you create a "subject profile" in the system. In order to provide payment, you will need to enter your name and date of birth into your subject profile. Depending on which payment method you choose, you may also need to enter your email address and banking information. If you already have an Advarra account (because you are in another study that uses this system), your existing profile will be used to provide payment. We can provide you with an "Information Sheet for Advarra Participant Payments" that details additional information. Your information will be shared with 'Advarra Participant Payments'.

Does this sound like something you'd be willing to participate in?

- If yes, continue below.
- If no, thank them for their time.

Before you agree to participate, there are some additional things you should know about the study.

The University of Rochester will make every effort to keep the information collected from you private. In order to do so, we will transcribe the focus group recordings in a secure manner, and recordings and transcripts will be stored on secure servers. Only the PI and relevant members of the research team will have access to these files. The transcripts will not include your name or other identifying information; you will be identified in the transcript by subject ID. Any follow-up interviews will also be transcribed in a similar de-identified manner, and stored in the same way as the focus group transcripts.

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. NIH (National Institutes of Health) is one of the organizations that may look at or receive copies of information in participants study records

In order to collect study information, we have to get your permission to use and give out your personal information. We will use research records such as survey forms and questionnaires, records about phone calls made as part of this research, and records about your focus group participation to conduct the study.

Your permission to use your personal information for this study will not expire unless you tell us you want to cancel it. We will keep the information we collect about you indefinitely. If you cancel your permission, you will be removed from the study.

Your participation in this study is completely voluntary. You are free not to participate 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.

If you are employed at the University of Rochester, taking part in this research is not a part of your University duties, and refusing will not affect your job. You will not be offered or receive any special job-related consideration if you take part in this research.

Do you have any questions? Do you agree to participate in this study?

☐ Yes: Document oral consent below and continue with the screening. If applicable, inform subject that they will receive an information sheet regarding the study for their records via mail or email.

☐ No: Thank them for their time.

Name of Subject:

_____

Person Obtaining Consent

I have read this form to the subject. 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. The subject has provided oral consent to participate in this study.

_____

Name and Title (Print)

_____ _____

Signature of Person Obtaining Consent Date