

Consent to Participate in Research

Study Title: Experiences of Individuals with Swallowing Disorders

Principal Investigator: Dr. Rebecca S. Bartlett

Summary of the Research:

You are being asked to participate in a research study. Your participation in this research study is voluntary and you do not have to participate. This document contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate.

You are being asked to participate in a study about the psychosocial burdens of swallowing impairments. The study consists of one virtual semi-structured interview that will take approximately 1-2 hours, and one questionnaire that you will be asked to return to the study investigators. Potential benefits may include providing future clinicians with insight about the effects of swallowing impairments. Your answers may help to create clinical tools and guidance.

Why is this study being done?

This is a research study being conducted to better understand the psychosocial burdens associated with swallowing impairments. Participants' answers may help future clinicians address these issues with future patients.

What will happen if I take part in this study?

You will participate in a virtual semi-structured interview and be asked to fill out one questionnaire that has nine questions. You will answer questions related to your experience living with swallowing impairment.

How long will I be in this study?

This study will take approximately 1-2 hours.

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How many people will take part in this study?

There will be up to 30 participants participating in this study.

Can I stop being in the study?

Your participation is voluntary, and you may leave at any time. There will be no penalty for withdrawal of this study. Your answers will not be used if you choose to leave the study.

What are the risks or benefits from being in this study?

You may benefit from discussing your thoughts, frustrations, and experiences with a knowledgeable researcher and clinician. There are no expected physical, social, legal, or economic risks associated with participation in this study. There could be a psychological or emotional toll that could come out of the interview. Northern Arizona University has no funds set aside for the payment of treatment expenses for the study.

Will I be compensated for participation in this study?

You will be compensated with a \$25 gift card for participation in this study.

Will my study-related information be kept confidential?

With your permission, I would like to video-record this interview so that I can make an accurate transcript. Your responses will be assigned a code number, and your name will not be in the transcript. The list connecting your name to the code will be kept on an encrypted, password-protected computer. Once I have made the transcript, I will erase the recordings. Identifiable research data will be stored on an encrypted and password protected computer. Your name will not be identified in any report or publication of this study. Because of the nature of the data, it may be possible to identify you; however, there will be no attempt to do so and your data will be reported in a way that will not identify you.

Will my study-related information be used for future research?

Coded data (i.e., data where your research code rather than your name is used as an identifier) from your interview may be used for future research or shared with another researcher for future research studies without additional consent. The information that you provide in the study will be handled confidentially. However, there may be circumstances where this information must be released or shared as required by law.

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Northern Arizona University Institutional Review Board may review the research records for monitoring purposes.

Who can answer my questions about this study?

For questions or concerns about this study, you may contact Rebecca Bartlett at Rebecca.Bartlett@nau.edu or 928-523-3561.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Research Protection Program at 928-523-9551 or online at <http://nau.edu/Research/Compliance/Human-Research/Welcome/>.

AGREEMENT TO PARTICIPATE AND TO BE VIDEO-RECORDED

I have read (or someone has read to me) this form, and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I affirm that I am at least 18 years of age and voluntarily agree to participate in this study.

I am not giving up any legal rights by agreeing to participate in this study. I will be given a copy of this form.

Investigator/Individual Obtaining Consent:

To the best of my ability, I have explained and discussed the full contents of the study including all of the information contained in this consent form. All questions of the research subject and those of his/her parent or legal guardian have been accurately answered.

Investigator/Person Obtaining Consent: Dr. Rebecca Bartlett